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THE UNIVERSITY OF ALBERTA

# AN EVALUATION OF PATIENT/FAMILY EDUCATION IN PEDIATRIC ONCOLOGY: THE OFF THERAPY PHASE

BY

LORRAINE M. DYNI (C)

A THESIS

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled An Evaluation of Patient/Family Education in Pediatric Oncology: The Off Therapy Phase submitted by Lorraine Dyni in partial fulfillment of the requirements for the degree of Master of Education in Counselling Psychology.

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Date: Aug. 31, 1989

Abstract

The purpose of this investigation was to determine the educational needs of parents whose children have been successfully treated for cancer at the Northern Alberta Pediatric Oncology clinic. All parents whose children have completed treatments for cancer in the past two years were invited to participate; sixty-six percent of this population responded to a mailed-out questionnaire.

Educational needs were evaluated using a questionnaire designed by the researcher as well as a physician, nurse counsellor and two educational psychologists. The questionnaire elicited both quantitative and qualitative data, and demonstrated high reliability and validity.

Results showed that information about the child's prognosis, diagnosis, feelings, side effects and the parent/child relationship are the five most important topics to parents whose children are in the off-therapy phase of treatment for cancer. Parents also indicated that they would prefer to receive more and continuous information about each of the education topics that were listed in the questionnaire.

One way Anovas showed there were no significant differences in parental information needs when subjects were grouped by disease type, length of time off-therapy, and parental sex.

Regression analysis showed that none of the demographic variables (parental age, education, distance from the hospital, and the child's age) were significantly correlated with parents' information needs.

Concerning educational format, parents indicated that they preferred to receive information about their child's physical and psycho-social needs verbally. Results also showed that parents prefer receiving information from a physician, nurse-counsellor and counsellor in each of their specialized disciplines.

Qualitative analysis showed that many parents were relieved and happy now that their child had completed treatments for cancer. Nearly equal numbers stated that they continued to be afraid of relapse and expressed uncertainty about the future.

## Acknowledgments

Throughout the course of this project several people have lent their expertise and encouragement. I wish to give special thanks to each of my supervisors: Dr. Kysela, for providing helpful feedback, suggestions and resources throughout the project; Dr. Jevne, who provided especially helpful guidance during the development of the questionnaire and consent forms; and Dr. Yanofsky who has been very generous with her time and thorough feedback from beginning to the end of this project.

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# Chapter I

## INTRODUCTION TO THE STUDY

Few life events parallel the difficult experience of having one's child diagnosed with cancer. In spite of the improved survival rate among childhood cancer patients, cancer continues to be the second leading cause of death among North American children (Canadian Cancer Statistics, 1988). As a result of the life threatening nature of the disease, enormous demands are placed on the family which tax even the most resourceful members.

Those involved in the health care profession continue to look for ways of helping families cope more effectively with the stresses caused by having a child with cancer. One such strategy has been to provide parents and patients with needed information through patient/family education programs (Thompson, 1986; Battista, 1986). It is recognized, however, that the kinds of information families need vary according to the stage and nature of the disease (Jenny, 1986), as well as the developmental level of the patient (Battista, 1986). Hence, educators must tailor educational materials to meet the changing needs and learning styles of patients and their families (Adams-Greely, 1986).

Today, because of aggressive treatment regimes, more children than ever are overcoming cancer, and a new population of long term survivors has emerged. In order to implement appropriate educational interventions it is imperative to explore in research, the information needs of long term survivors and their families.

## Background To The Problem

Research on survivors of childhood cancer and their families is a sensitive and important area. The number of children who have been cured of cancer has increased significantly over the last ten years, and a new population of "off-therapy" patients or "long term survivors" has emerged. Although such advances are encouraging, evidence has been garnered to suggest that being cured of cancer in childhood may engender a whole new set of problems for survivors and their families. In an extensive review of the literature on the psychosocial aspects of childhood cancer, Van Dongen-Melman and Sanders-Woudstra (1986) concluded that:

> The literature strongly indicates that families experience serious difficulties and are a population at risk of developing psychosocial problems. (p. 240)

Although the nature of these problems is an ongoing research issue, the above statement also reflects an

evolving premise among health care professionals. More specifically, there is growing acceptance of the fact that absence of disease constitutes an essential but single component of health and wellness. As such, patient/family education has become a valuable ally in promoting an wholistic view of health. In general, health education has shown its effectiveness by improving patients compliance to regimens (Young, Jorgenson & Shapiro, 1986; Lucey and Wing, 1985), by helping patients cope with the stress and emotional impact of illness (Johnson, 1982) and has also helped to advance the practice of preventive medicine.

In spite of the apparent merits of health education little research has been done in the area of patient/family education in pediatric oncology. Because of the growing population of survivors of childhood cancer, education of patients and families about long term sequelae is imperative. The goal of this study then, is to conduct an exploratory investigation to determine parents information needs, as well as their preferences for format and timing of information, now that their child is in the "off-therapy" phase of treatment.

## Statement Of The Problem

Childhood cancer is no longer a uniformly fatal illness (Pfefferbaum, 1980; Van Eys, 1977, 1981). Statistics collected by Hockenberry and Coody (1986) show that over 6,000 cases of cancer will occur in children under 15 years old in the United States each year; over one half of these children will be cured of their disease. As a result of this growing success rate, health care professionals are now challenged to help families cope with the "off-therapy" phase of a child's treatment.

Another significant change in the health care system over the last few decades has been the trend among medical professionals to invite increased levels of participation and responsibility from the patient for his/her own health care (Chesler and Barbarin, 1987). Implicit in this model, is the need for health care professionals to effectively educate the patients that they serve. The task of educating families in which children have overcome cancer is made difficult by a number of variables. One important variable is the insufficient as well as inconclusive evidence outlining both the emotional and medical concerns of survivors of

childhood cancer and their families (Van Dongen-Melman and Sanders-Woudstra, 1986; Leonard and Waskerwitz, 1986). Research on the broad topic of patient education has also failed to clearly demonstrate whether timing and method of information delivery significantly influence the effectiveness of patient/family education.

In view of the lack of evidence on families' information needs and format preferences, this study will assess what kinds of information needs families have, and what instructional methods they prefer now that their child is in the off-therapy phase of treatment for cancer.

## Importance Of The Study

Research literature on patient/family education has underscored the importance of having parents and patients indicate their information needs and concerns. Studies have demonstrated significant differences in medical professionals' perceptions of information needs and parent/patient stated concerns (Lauer, Murphy & Powers, 1982; Chesler and Barbarin, 1984; Pfefferbaum, 1980). In a particularly relevant study conducted by Coulter and Koester (1985) with parents of epileptic children and the physicians involved in their childrens'

care, results showed significant differences in physicians' and parents' concerns. Moreover, the researchers noted that physicians tended to underestimate the psychosocial concerns of parents and patients, while overestimating medical concerns. Further study on the psychosocial concerns of survivors of childhood cancer and their families is recommended by researchers (Koocher and O'Malley, 1981; Wallace, Reiter, & Pendergrass, 1987; Leonard and Waskerwitz, 1986). Tentative conclusions have been drawn about the nature of parental and patient concerns at this stage of treatment and these include concerns about visible physical impairments, opportunities for marriage, health of progeny, employment and insurance difficulties (Koocher and O'Malley, 1981), as well as concerns about the child's emotional development and relationship with siblings and family (Wallace et al., 1987). Continued research in this area is necessary in order to validate or refute these claims.

Equally important is the need for additional exploration of patient/family education. Numerous authors have contributed anecdotal literature citing the value of patient/family education (Adams-Greely, 1986;

Korsch, 1984). Some research has compared the effectiveness of various educational formats (Jacobs, Ross, Walter & Stockdale, 1983; Young, Jorgenson & Shapiro, 1986) or the effectiveness of timing on information delivery (Huchcroft, Snodgrass, Troyan, & Wares 1984).

To date, there is a paucity of research literature on the topic of patient/family education in pediatric oncology (Leonard and Waskerwitz, 1980), and questions about the importance of content, format and timing of information remain unresolved. The present study provides a unique synthesis of two related areas of research, that of the sequelae of surviving childhood cancer, and patient/family education.

The exploratory measures used in this investigation add a new dimension to existing research on both topics, and help to identify questions which require more in-depth examination. The practical implications of this study stem from the fact that information gathered may facilitate the development of an improved educational program for off-therapy patients and their families who come to the Northern Alberta Pediatric Oncology Unit.

# Chapter II

## HISTORICAL OVERVIEW OF PATIENT/FAMILY EDUCATION

Patient/family education has become a crucial component of health care over the last three decades. The evolution of patient/family education from incidental and random occurrences, towards more systematic well-defined programs, can be attributed to a series of socio-historical events and trends. A brief outline of this history will be presented here in order to contextualize a review of the research literature on patient/family education.

Most authors who research the field of patient/family education agree that interest in this area of health care has increased rapidly over the last 25 years (Cohen, 1980; Johnson and Blumberg, 1984; Kramer and Perin, 1984). Yet formative influences of patient/family education can be traced back as early as 1918 when the National League of Nursing Education in the United States noted the importance of health teaching (Cohen, 1980). A second and perhaps more important event occurred in the 1950's when prepaid health care plans were established in the U.S.A. The principle that "informed self-care could reduce long-range patient care costs" served to advance

the development of patient/family education (p. 8, Johnson and Blumberg, 1984). Another important event occurred in 1964 when the American Hospital Association stated that its responsibility was to stimulate the development of patient education nationwide (Johnson and Blumberg, 1984). This event, like each of the others, signified a growing public awareness in patient/family education.

Stronger and more recent influences have led to greater commitment on the part of health care professionals to consider patient/family education as a priority. The Helsinki Conference (1972) on informed consent was one force which indirectly influenced the development of patient/family education. A consequent result was the view that informed consent could be more easily achieved through patient education programs (Kramer and Perin, 1984). Another catalyst was the "Patient's Bill of Rights" which was legislated in the United States in 1973. This document ensured the right of a patient to "obtain complete, current information concerning diagnosis, treatment, and prognosis in terms he can reasonably be expected to understand" (p. 8, Johnson and Blumberg, 1984).

Social trends such as the consumer's rights movement, (Kramer and Perin, 1984; Johnson and Blumberg, 1984), the increased emphasis on disease prevention, and a growing population of chronically ill persons (Somers, 1976; Schoenrich, 1976) have also shaped the development of patient/family education. Moreover, recent technological advances as well as an interest in decreasing health care expenditures has underscored the importance of patient/family education (Tabak, 1987). In short, the phenomenon of patient/family education reflects an historical movement in which the active participation of both medical professional and patient is advocated so that mutual responsibility for health care can be assumed.

A definition of patient/family education is important at this point. Various descriptions have been applied, but Bartlett (1984) a physician, defines it well in the following:

> Patient education is the broadest of the three terms (informing, counselling and teaching) and encompasses both counselling and teaching activities (p. 921, Bartlett, 1984).

Bartlett's definition suggests that patient/family education deals with emotional as well as physical aspects of having an illness. In retrospect, both this

definition, as well as the historical sketch of the evolution of patient/family education, provide an important context for a review of the literature in this area.

## Literature Review

The research literature around patient/family education remains fragmentary and diverse. In a review of patient education literature Cohen (1980) divides it into two categories. The first is non-research literature consisting of theoretical concerns and program reports (LaFortune-Fredette and Beattie, 1986); the other is research literature comprised of experimental works. Numerous topics have been explored within the two perspectives, and each has been developed to varying degrees. This investigation consolidates some of the gains made in research on patient/family education. The aspects to be examined include the content and timing of patient/family education programs, the relationship of demographic variables to information preferences, and the effectiveness of different teaching methods. Also noteworthy is the fact that cancer patient/family education research is part of a larger body of patient education studies.

## Content of Patient/Family Education

Studies dealing with the content of patient education come from both the research and non-research streams. Non-research narratives which look at the content of education programs tend to be disease specific, and are often directives about what to teach patients (Cohen, 1980). Looking specifically at cancer patient education, recent efforts from the non-research category include the work of Crosson (1984) who discusses the range of methods for educating cancer patients, as well as the kinds of information that are most salient at different phases in the disease trajectory. Another article by Johnson and Blumberg (1984) summarizes the educational needs of cancer patients, and the authors conclude that patients' medical and emotional concerns need to be addressed. Wofford (1987) identifies patient/family education as one of the central responsibilities of the pediatric oncology nurse, and she describes the kinds of information required by patients who successfully complete treatments.

From the research literature perspective, a descriptive study by Alt (1966) stands out as a most pertinent work. Using a sample of 450 patients at

Beverly Massachusets Hospital in Boston, Alt conducted open-ended interviews as a way of determining what patients wanted to know at the time of their discharge. Results of the study showed 51% of the patients had no lingering unanswered questions while 49% indicated that they did have unanswered questions concerning post-discharge activities, their real diagnoses, and the symptoms of their disease.

The perceived learning needs of 50 adult cancer patients were assessed by Johnson (1979) using informal interview methods. The three most important concerns expressed were : 1) acquiring accurate and current information on the disease process and treatment plan, 2) accepting and readjusting to changes in body image and self-concept and 3) learning to express feelings about having the disease.

Jones, McClellan, Shani, Pellegrini, Grover, Engstrom (1982) conducted a needs assessment to ascertain cancer patients' preferences for educational content, as well as methods and media. From an outpatient population of 122 adults, the researchers used open-ended interview questions to obtain their data. While most patients reported that they received adequate amounts of

information about their illnesses and treatment (66% and 69% respectively) there were suggestions for additional content. Some of those suggestions included: reasons for a procedure or treatment, possible side effects, and expected outcomes of treatment. The authors noted that there was considerable variation in the amounts of information that patients desired.

In another study by Pfefferbaum and Levenson (1982) adolescent cancer patients' information concerns were compared to physician's perceptions of their informational concerns. Subjects for the project included 63 adolescent patients ages 11 to 20 years and 53 physicians with a mean age of 34 years; all subjects were asked to rate the importance of disease-related information topics. Data analysis showed that physicians and patients differed significantly on 15 out of the 30 items that were presented. Examples of concerns that adolescents identified as more important were: what to expect if their cancer spreads, how cancer can be prevented, and what causes cancer. This discrepancy between patients' perceived needs and the views of professionals has been noted by other researchers as well (Chesler and Barbarin, 1984; Lauer et al., 1982). Other

studies have shown patients preferred receiving more information about the psychosocial aspects of their illness, while health care professionals emphasized the importance of providing medical information (Coulter and Koester, 1985; Stern, Maoz, Leiser, 1982).

By way of contrast, there is also evidence to suggest that cancer patients see themselves as adequately informed about their illness and the support services available to them (Edwards and White, 1987). Even more interesting were the results of a study carried out by Falvo and Tippy (1988). Their work demonstrated that patient satisfaction was due to patients' perceptions of physicians' attempts to give them information, rather than the actual information given.

Inconsistent results around research on the information needs of patients and families could be attributed to the dearth of valid and reliable instruments available for assessing patient needs and preferences (Volker, 1987; Sutherland, 1986).

Dodd and Ahmed (1987) suggest that:

> The degree of involvement a patient perceives as optimum in a situation such as radiation therapy is variable and so may the patients' preference for information. Possibly clinicians provide the non-preferred type of information. This may

> in part explain the documented poor retention of information and lack of self-care activities to manage side effects. A reliable and valid instrument to determine such preference would be useful in clinical research and practice. p. 240.

The directive given by these authors can be directly applied to the area of pediatric oncology since, to date, no research has investigated the information needs of long-term survivors of childhood cancer and their families.

While some gains have been made in understanding the information needs of cancer patients and their families, overall it appears that continued investigation in this area is needed.

## Timing of Information

In conjunction with concerns over what information patients should have, some question has arisen as to when is the most appropriate time to deliver information. Numerous authors have recommended that the timing of information is important and that the stage of disease must be accounted for in determining the kinds and amounts of information needed by the cancer patient (Welch-McCaffery, 1985; Bartlett, 1984; Korch 1984; and Battista, 1986).

There is a paucity of experimental data around the

issue of timing of information and there do seem to be conflicting results about the importance of time. Alt (1966) concluded from his study that the time at which information is given is a critical variable mediating whether or not patients perceive that they have received adequate amounts of information. By way of contrast, Newal, Gadd and Priestman (1987) showed that patients in both the United Kingdom as well as the United States were satisfied with the timing of the confirmation of the diagnosis and the reporting of treatment progress. In summary, there seems to be a good deal of non-research literature suggesting that the timing of information delivery is crucial, but there is minimal evidence to support this.

## Demographic Variables

Cassileth, Zupkis, Sutton-Smith & March (1980) have called attention to the relationship between demographic characteristics and the information preferences of cancer patients. Cassileth et al. (1980) collected demographic data from 256 cancer patients from the University of Pennsylvania Hospital. Data analysis revealed significant age trends as younger patients preferred to be well informed about their disease while older patients

liked a more "non-participatory" approach. Geographical location also appeared to be an important variable influencing the patient education process as reported by Rudolph, Pendergrass, Clarke, Kjonness & Hartman (1981). The results showed that families living at a distance from the treatment centre experienced more stress because they were uncertain of their knowledge. Other influential variables included parental age, education, socio-economic level, cultural orientation, language and the parents preferred past information preferences (Chesler and Barbarin, 1984; Kramer and Perin, 1985).

## Educational Formats

Research has shown patient/family education to be an effective method for attenuating the negative impact of a number of illnesses. Recent studies have demonstrated that health education is helpful in reducing the anxiety and/or depression that frequently accompany a serious illness (Forsuis, Jansson, Jarvinen & Piilenen 1985; Doroshow and London, 1988; Bradlyn, 1986) as well as being a useful tool for increasing patients' control of pain (Rimer, Levy, Keintz, MacElwee & Engstrom, 1987; Larsson and Melin, 1986). Patient self management has also improved when educational measures have been

implemented (Evans, Clark, Feldman, Rips, Kaplan, Levison, Wasilewski, Levin & Mellins, 1987; Powell, 1988; Baum and Creer, 1986). In the majority of studies, patient education has been more effective in helping patients and families cope with sequelae of having an illness than when no educational intervention was received by patients and their families.

Studies examining the efficacy of different teaching methodologies often do so by measuring the differences in subjects' ability to retain information. Hassell and Medved (1975), for example, compared 50 minutes of group audiovisual instruction of diabetic patients with 15 minutes of bedside instruction. A total of 45 subjects were assigned to one of two treatment groups and a control group, and their knowledge was measured before and after instruction usign a questionnaire. Both treatment groups demonstrated significant gains with instruction.

Young et al., (1986) compared three methods of conveying genetic related information to parents of children with cleft palate. Sixty-one subjects were tested for long-term retention of information as well as their preferred method. Among the three formats of

slide-tape, individual counselling and group counselling, no significant differences were noted in efficacy or preference.

From the perspective of cancer patient education, Fulginiti (1984) contends that educators should attend to the form of educational material. Whether these be video or pamphlet, the format should allow the information to be readily received by families. Kramer and Perin (1985) also recommend that the selection of educational format (ie. group, individual, written, visual, audiovisual) should be tailored to the learner, therefore it is essential to assess the learner's language and level of stress before providing information.

The earlier mentioned needs assessment carried out by Jones et al., (1982) confirmed that patients desired a variety of methods and media to meet their informational needs. While 66% of patients said they would like additional written material, 42% favored audiovisual information, 35% wanted additional counselling by a physician and 35% desired peer groups discussions.

A tentative conclusion that can be drawn from these studies is that while there appears to be little difference in the efficacy of various educational

formats, patients' preferences do differ and need to be assessed in order to maximize learning potential.

# Chapter III

## SURVIVORS OF CHILDHOOD CANCER

The child's treatment is considered successful when the disease has gone into remission and the remission is maintained for an extended period of time. Children who do not experience a relapse of the disease and no longer receive treatments are called off-therapy patients. The child who continues to be disease free five years after treatments is generally regarded as being "cured", and becomes a long-term survivor of childhood cancer.

The population being examined in this study is children and families who have successfully completed treatments for cancer within the last two years, who are not regarded as off-therapy patients.

The late effects experienced by off-therapy patients, long-term survivors, and their families is gradually being documented in the research literature. Long-term sequelae have been observed in both the physical-cognitive and psycho-social domains of children's lives; they will be briefly reviewed at this point.

## Late Effects of Childhood Cancer

Present treatment regimes for pediatric cancer patients are often intensive multi-modal therapies which are a combination of chemotherapy, radiotherapy and surgery.

In spite of the fact that these aggressive treatment protocols work to destroy cancerous cells, they also impact normal body cells. Consequently, children experience some temporary side effects during treatment such as hair loss and nausea, as well as more permanent effects such as those sustained from amputation. From recent investigations it is apparent that still other sequelae may surface months or years post treatment. Gotay (1988) suggested that some potential very late effects may not yet have been identified. A brief review of some of the late sequelae of childhood cancer will follow.

### Physiological Effects

It is beyond the scope of this paper to provide a comprehensive review of the physical side effects that occur in the pediatric oncology population. The abundant research in this area has shown that both the disease and its treatment can have wide-ranging effects. Virtually

every body system is vulnerable to damage including: the cardiovascular system; endocrine system; gastrointestinal system; musculoskeletal system; nervous system; respiratory system; and urinary tract.

Long-term effects have emerged from immunosuppression, amputation, and problems have also been noted in visual, auditory and dental areas. Several thorough literature reviews describe these effects in greater detail (Byrd, 1985; Dobkin and Morrow, 1985; McCalla, 1985; Meadows and Silber, 1985, Ruccione and Fergusson, 1984).

Adverse effects on growth and development including stature and sexual maturation have been recorded. There is a small amount of data exploring whether the future progeny of childhood cancer patients may be affected by treatments received by their parents (Poplack, Cassady, and Pizzo, 1985). The possibility of developing a second neoplasm is also of concern for these patients and research bears out that they are at 10 to 20 times greater risk than the general population.

## Cognitive Effects

The impact of radiation and chemotherapy on children's cognitive abilities is not clearly understood at this point. Most research on neuropsychological toxicity has been done with leukemia and brain tumor patients.

The available evidence on leukemia patients suggests that there is a link between cognitive deficits and cancer therapy (Fletcher and Copeland, 1986). Fletcher and Copeland drew this conclusion after they reviewed 40 studies on the effects of prophylactic central nervous system treatment on neuro-behavioral development. Deficits were more frequently noted on non-language tests, rather than on language tests, and among children who received therapy at an earlier age. Reviews conducted by Poplack & Brouer (1985) and Stehbens, Kisker & Wilson (1983) on this issue contain similar findings.

More serious late term effects have been observed among survivors of brain cancer, and are reported in various literature reviews such as Kun, Mulhern, & Crisco (1983) and Stebhens et al., (1983). Duffner, Cohen and Freeman, (1985) remarked in a literature review that children who are treated with cranial radiation often

perform in the "retarded" range (p. 298) whereas survivors of leukemia generally function in the average range of intelligence.

It is apparent that researchers have difficulty interpreting the results of research because of methodological drawbacks such as "small sample size, lack of adequate control groups, failure to consider age at diagnosis, use of neuropsychological test batteries that are too insensitive to detect specific kinds of deficits, as well as varying effects in response to different diseases and treatments" (Gotay, 1988; p.7)

These limitations preclude the formulation of generalizations other than to say that neuropsychological toxicity may be broad, including both global and specific cognitive deficits.

## Psychosocial Effects on Survivors

It is difficult for researchers to evaluate the psychosocial effects of having childhood cancer. This difficulty arises from the fact that psychosocial problems may have been present prior to the occurrence of cancer. Nonetheless, research on this topic has yielded valuable information.

Early studies which investigated the psychological aspects of childhood cancer suggested that no major psychosocial problems were encountered by survivors. One-hundred and twenty-four pediatric cancer survivors were studied by Holmes and Holmes (1975). Subjects were evaluated for their educational achievement, marital and family status, and their attitudes towards cancer. Approximately 25% of those sampled who were over 20 and unmarried believed their previous disease prevented them from finding a marriage partner. A small group (21 subjects) reported that they had problems and lifestyle alterations as a result of the disease. Overall, however, the majority of subjects reported doing well in all the areas measured.

Li and Stone (1976) found similar results when they evaluated 145 pediatric cancer patients who had been disease free for five or more years. The researchers noted no differences between the experimental group and the general population along the dimensions of education, employment, and marital or family status. More recently, Li, Winston, and Gimbrere (1984) reached similar conclusions from their study. Fergusson (1976) also showed that severe adjustment problems do not always

occur in long-term survivors of childhood cancer. The study, with a small sample of 18 participants, showed only two subjects with moderate to severe adjustment problems, and these could not be attributed solely to their illness.

A comprehensive project by Koocher and O'Malley (1981) presents results which contrast with previous studies in this area. Intensive study of 117 survivors of childhood cancer was carried out by the researchers. A variety of psychiatric and psychological tests and interviews were administered to evaluate the subjects' psychosocial well-being. A control group was assembled in order to identify any distinct characteristics of the pediatric cancer population. Family members were also given a battery of tests and interviews. In general it appeared that approximately 50% of those who participated has some mild psychiatric symptoms; the percentage of unmarried female survivors was larger than the percentage unmarried in the general population, and about 40% of the participants said they experienced employment discrimination, and some had difficulty purchasing life insurance. The authors concluded that overall, this population was "at substantially greater psychological

risk than are the survivors of other chronic, but not life-threatening childhood illnesses." (p. 72)

Other studies have supported the findings of Koocher and O'Malley (1981). With regard to psychological difficulties, several studies with brain cancer survivors demonstrated a high prevalence of psychological problems. Bamford, Jones, Pearson, Ribeiro, Shalet, Beardwell (1976) noted that 43% of the survivors they tested had "significant emotional problems" with aggression, isolation and emotional lability being most common. Hirsch, Renier, Pierre-Kahn, Benveniste, George (1978) found that 91% of the 23 medulloblastoma survivors exhibited problems such as tardiness, anxiety, aggression and isolation, as well as behavioral and attentional difficulties. Likewise, in a study by Danoff, Cowchock, Marquette, Mulgrew & Kramer (1982), 37% of 38 brain cancer survivors demonstrated emotional problems such as immaturity, depression, antisocial tendencies, and fearfulness. Sixty-two percent of brain cancer survivors showed evidence of psychiatric symptomology in a study of 21 survivors by Kun, Mulhren & Crisco (1983). Zwartes (1980) also reported that brain cancer survivors showed signs of depression and led an isolated lifestyle.

In a recent study by Moore, Glasser & Ablin (1988), the social and emotional functioning of 35 school children who were survivors of leukemia or solid tumors (not involving the CNS) were evaluated using the Deasy-Spinetta Behavioral Questionnaire. The majority of these subjects achieved scores at a level below school peers.

Evidence of employment difficulties was reported by Feldman (1980) who investigated 78 people (aged 13-23) who had been cancer patients. The results suggested that about 25% of subjects who were employed had experienced work problems related to their cancer. Job discrimination was also a concern among one third of the sample. Similarly, Teta, Pobel, Kasak, Wister-Meigs, Myers & Mulvill (1986), in a study which used both survivors (N=450) and their siblings (N=587), reported that male survivors were more frequently rejected from college and employment than their male siblings. It also appeared that both male and female survivors encountered significantly more difficulty securing life and health insurance. This finding was replicated in a similar study by Holmes et al. (1980).

## Psychosocial Effects on Families

Very few studies have examined the long-term sequelae of having a child with cancer on the entire family. Koocher and O´Malley (1981) studied the parents (N=119) and siblings (N=101) of survivors in their primary study, as well as an independent sample of 15 parents whose children were adolescents. The findings indicated that parents continued to worry about the disease; their concerns included recurrence of the cancer, an increased vulnerability to other forms of cancer, the child´s difficulty forming lasting relationships with members of the opposite sex, and concerns that the cancer history might impede the survivor´s vocational opportunities. Parents also expressed concern over having given inadequate attention to the needs of the other children in the family.

A current study by Wallace et al., (1987) attempted to have parents identify their major stresses and concerns now that their child had completed treatments for cancer. A number of concerns were expressed, the three most frequent being 1) worry about the survivor´s ability to have children 2) worry about the physical side effects of the illness 3) worries about marriage and dating.

Another study which investigated the impact of long-term survival on families was carried out by Obetz, Swenson, McCarthy, Gilchrist & Bergert (1980). Parents were asked to complete the MMPI, the Gough Adjective Checklist, and two Q-Sorts examining their child's behavior and their own attitudes and behaviors. The sample was comprised of parents whose children had been in remission from leukemia for four or more years. Results indicated that many parents continued to be troubled by their child's illness. The research team noted that fathers appeared to have more difficulties than mothers.

Danoff, Cowchock, Marquette, Mulgrew & Kramer (1982) also administered the MMPI to 36 parents of brain cancer survivors and found that 59% of mothers and 43% of fathers exhibited behavioral disturbances and demonstrated overprotective attitudes towards their children. In an earlier study by Peck (1979), parents (N=24) whose children had survived ALL or Wilm's tumor for at least two years, were interviewed by a social worker. In most cases, parents reported that they experienced family difficulties such as problems with siblings, school-teacher's treatment of the "cured" child

and financial strain. Lansky and List (1986) and Koocher and O´Malley (1981) also found that financial difficulties became a long-term stress for the families that they studied.

# Chapter IV

# FAMILY STRESS AND COPING

Up to this point some of the long-term physical, cognitive, psychological and social sequelae which may accompany survival have been examined; the importance of educational programs for patients and families with chronically ill members was supported in a review of the literature on patient/family education. Such programs are especially valuable to pediatric oncology patients and their families (Wofford, 1987). The review also made it evident that many questions concerning the appropriate content, timing and format of educational programs have yet to be resolved.

Clearly, there is a relationship between research on the long-term effects of cancer survival, and the development of effective educational interventions. One way of elucidating this relationship is through a conceptual model which describes the process of stress and coping. A theoretical framework of stress and coping, and its application to surviving childhood cancer will be presented here.

## Crisis Stress Model

Early research (1950-70) which explored the effects

of long-term childhood illness or handicap on families assumed that childhood illness created family stress and almost invariably resulted in psychopathology for individual family members (Gayton, Friedman, Tavormina & Tucker, 1977). According to Young (1983) and Longo and Bond (1984) this hypothesis can be translated into a crisis-stress model where the A (crisis) leads to X (psychopathology).

This paradigm has been used in studies related to cystic fibrosis (Allan, Townley & Phelan, 1974; Turk, 1964), congenital heart disease (Apley, Barbour & Westamacott, 1967); mental retardation (Gath, 1972; Holt, 1958; Kaplan; 1969, San Martino & Newman, 1974) spina bifida (Tew & Lawrence, 1973) and childhood cancer (Binger, Albin, Feuerstein, Kusher, Zoger & Mikkelson, 1969; Cain, Fast, & Erikson, 1964; Cairns, Clark, Smith & Lansky 1979, Gogan, Koocher, Foster & O´Malley, 1976, Kaplan, Grobstein, & Smith, 1976, Peck; 1979, Spinetta and Deasy-Spinetta, 1981, Teitz, McSherry, & Britt, 1977; Wold and Townes, 1969). Brett (1987) points out that these studies contain numerous methodological weaknesses such as experimenter bias, non-representative sampling, lack of statistical tests of significance and incomplete

interview techniques.

More recently, researchers using the crisis stress model have suggested that the A (crisis) produces X (psychopathology) formulation may be oversimplified. Methodological refinements which strengthen the validity of their work show that the adjustment of family members to chronic illness or a child's handicap, is related to a number of variables such as characteristics of the child, siblings, parents and the nature of the child's handicap. A relationship between the type of chronic childhood condition and the adjustment of family members has been demonstrated by several investigators (Simeonson and McHale, 1981; Lavigne and Ryan, 1979, and Gath, 1972). Overall, these studies suggest that it may be important to investigate the unique circumstances of such conditions as "cured" childhood leukemia rather than draw generalizations from other populations (Jones-Jessop and Stein, 1985; Pless and Pinkerton, 1975)

## Family Systems

A theoretical perspective which is becoming increasingly important is that which views the family as a system. According to Reiss (1978) a systems approach holds that families are more than the sum of their

individual members. As such they develop coherent patterns by which individuals collaborate to respond emotionally, solve problems, and resolve conflict.

Research literature on stress and coping which uses this model as its theoretical base, investigates family interaction, rather than individual psychopathology (Desmond, 1980). Brett (1987) concludes that the family systems perspective contributes in two distinct ways to the literature. First, systems theory promotes a more complex analysis of stress and coping. Secondly, this perspective acknowledges the critical role of individual appraisal in determining coping responses of family members (Walker, 1985). One often cited paradigm that describes the stress and coping responses of families with chronic childhood illness is described by Brett (1987, p. 20) in the following:

> In an effort to tie together the multiple facets of family response to chronic childhood illness, several family systems oriented researchers have used the stress response model of Hill (1958) where A (stressor event characteristics) interacts with B (family resources) and C (the family definition of the event) to produce X (the family crisis).

The basic tenet of this model is that a crisis or stress response is produced by an interactive "fit" between individual, family, situational and societal

characteristics (Montgomery, 1981).

Hill's 1958 model has been further developed by McCubbin, Cauble & Patterson (1982) and McCubbin and Patterson (1983) in the Double A B C X model of family behavior. McCubbin and Patterson (1983) point out that their enlarged model adds post crisis variables to Hill's model in an attempt to describe the following:

a) the additional life stressors and strains which shape the course of family adaptation;

b) the critical psychological, intra-familial, and social resources families acquire and employ over time in managing crisis situations;

c) the changes in definition and meaning families develop in an effort to make sense out of their predicament;

d) the coping strategies families employ;

e) the range of outcomes of the family efforts (McCubbin and Patterson, 1983, p. 11)

## Family Coping

Studies which have examined family coping with chronic childhood illness suggest that individual psychopathology is not an inevitable outcome (Gayton, Frieddman, Tavorimina & Tucker, 1977; Schulman, 1983).

Futterman and Hoffman (1973) found that in many cases families reported a positive redefinition of values and increased family cohesion because they had a chronically ill child. Moreover, a number of researchers point out that family responses may appear pathological when viewed in isolation, but may actually be adaptive when considered in context (Desmond, 1980; Futterman and Hoffman, 1973; Graliker, Fishler & Koch, 1962; Kupst and Schulman, 1980; Chesler and Barbarin 1987).

When research literature on family coping is compiled, five main strategies appear to be associated with "successful adaption". These include the use of social support (Holoday, 1984; Kazak and Marvin, 1984; Krulik, 1980; Schilling, Gilchrist and Schinke, 1984; Schulman, 1983; Spinetta and Maloney, 1978, Venters, 1981), achieving mastery (Futterman & Hoffman, 1973; Holoday, 1984, Iles, 1979; Krulik, 1980), normalizing the situation for the family (Anderson, 1981; Anderson and Chung, 1982; Futterman, and Hoffman, 1973; Graliker et al., 1962; Holoday, 1984; Krulik, 1980; Schulman, 1983), assigning meaning to the situation (Futterman and Hoffman, 1973; Spinetta and Deasy-Spinetta, 1981; Venters, 1981), using open family communication

(Delcampo, Chase and Delcampo, 1984, Krulik, 1980; Schulman, 1983; Spinetta and Maloney, 1978). To this end, patient/family education may enhance the family's ability to achieve mastery over a stressful situation.

In view of the fact that patient/family education may ameliorate family coping, the following questions will be answered in this study:

1. a) What are the information needs of parents whose children have completed treatment for cancer since 1986?

   b) Are there significant differences in the information needs of parents whose children recently came off-therapy (1987-88), and the information needs of parents whose children have been off-therapy since 1986?

   c) Are there significant differences in the information needs of parents whose children have been treated for Leukemia and Non-Hodgkins Lymphoma, and those whose children have been treated for other forms of cancer?

   d) Are there significant differences in the information needs of males and females?

2. a) What is the emotional experience of parents when their child is in the off-therapy phase of treatments?

   b) Do parents want more information about the kinds of parental stresses that are common to this phase of treatments?

3. Do parents find that the information that they receive now that their child has completed treatments for cancer is given to them at a "helpful time"?

4. What is the relationship between selected demographic variables and parents' stated information needs?

5. a) What educational formats do parents prefer for different information topics?

   b) From whom do parents most prefer to receive information for different information topics?

# Chapter V

# METHOD

## Sample

All parents whose children were successfully treated for cancer at the Northern Alberta Pediatric Oncology Unit, and have been in the off-therapy phase of treatment since 1986 were asked to participate in the study. Altogether 36 families fit these criteria; 30 were two parent families and six were single parent families. Of the single parents, 5 were single mothers and one was a single father. All together 66 subjects were asked to complete the questionnaire.

Of the families invited to participate, 39% reside in the city of Edmonton. Another 56% of the sample live in small communities across Alberta, and two families who live in provinces outside Alberta make up the remaining 59% of the sample. Several disease types are represented by the children in the sample, and these include: Acute Lymphoblastic Leukemia (ALL), Acute Myelogenous Leukemia (AML), Hodgkin´s disease, Non-hodgkin´s lymphoma, Wilms´ tumor, Neuroblastoma, Ewing´s sarcoma, Osteogenic sarcoma, Rhabdomysocarcoma, Hepatoblastoma, and Retinoblastoma. The sample was selected as a

representative one in view of its practical significance to the Northern Alberta Pediatric Oncology team.

Completed questionnaires were returned by approximately 66% of the entire sample. A total of 24 families participated in the study. Three of the families were from the group of single mothers, and in two cases, only one parent returned a questionnaire from the group of two parent families. The actual sample consisted of 42 subjects.

Parents who participated in the study had varying levels of education, and Figure 1 provides an indication of the number of parents at each educational level. The majority of parents (52%) had received some post secondary education and 38% had completed high school.

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Insert Figure 1 about here

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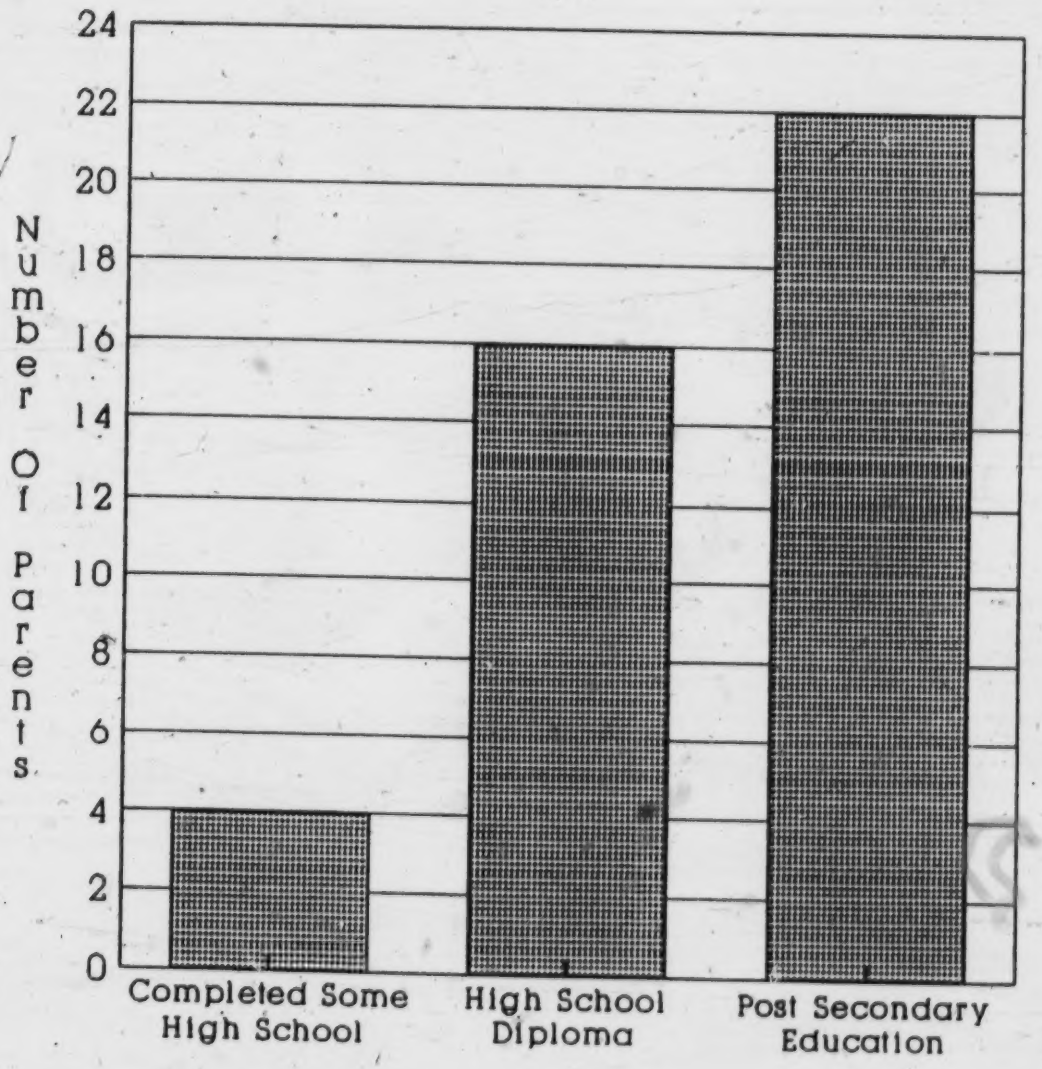
Figure 1



Education Level Of Parents




Education Level Attained By Parents

The location of families who participated in the study is presented in Figure 2. The graph shows that 42% of the families live within 50 miles of the city of Edmonton and 58% of the sample live 100 miles or more outside of Edmonton.

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Insert Figure 2 about here

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The children who were represented in the final sample ranged in age from 2-17 years old at the time they completed treatments for cancer. Figure 3 shows the number of children found in various age groupings. The median age of the children at the time they completed treatments was 7-8 years old. Also, 15 children in the final sample had had blood related cancers such as ALL, AML, Hodgkins' Lymphoma and Non-Hodgkins' Lymphoma. The remaining 9 children had been diagnosed with solid tumors.

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Insert Figure 3 about here

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Figure 2



Distance Of Families From Hospital

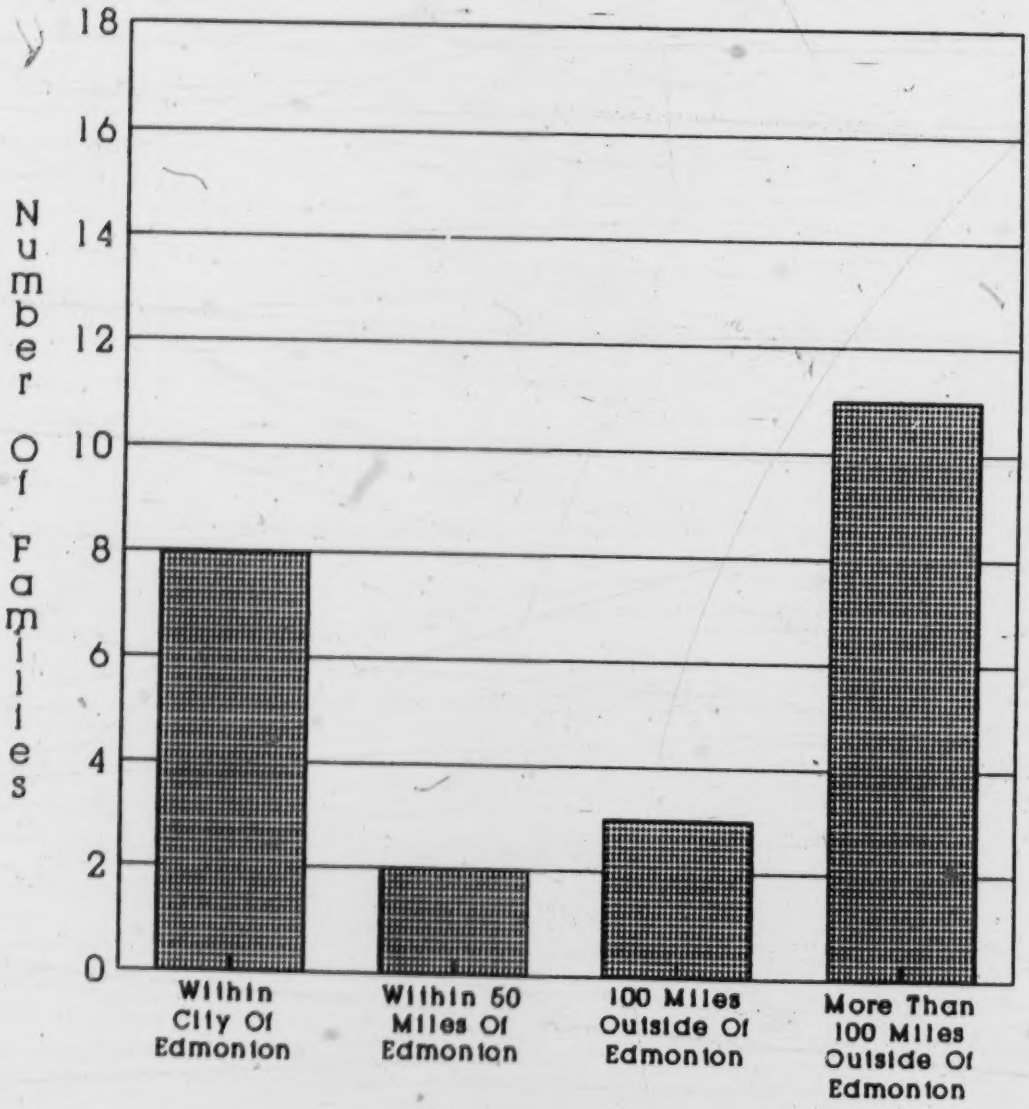
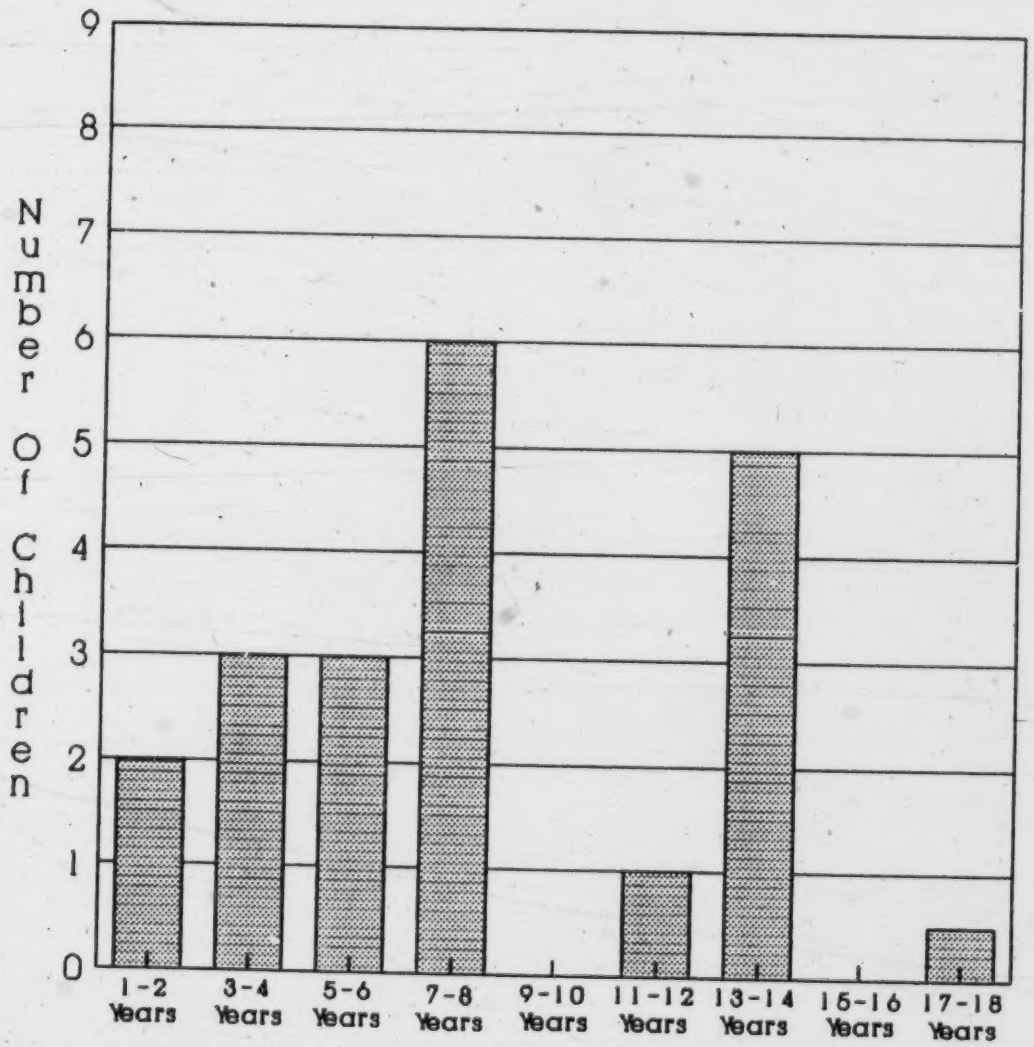


Figure 3



Ages Of Children When Taken Off-Therapy



Instrumentation

A questionnaire (Appendix A) was designed by the researcher in collaboration with a physician and nurse counsellor, who were specialists in the area of pediatric oncology, as well as two educational psychologists. The questionnaire is divided into five sections, so that both quantitative and qualitative information could be examined. Consequently, the questionnaire solicits information from parents with regard to the following topics.

1.a) The importance of specific informational topics is evaluated. The topics were generated by members of the pediatric oncology team, as well as from research literature on children who are long-term survivors of childhood cancer.

Part II A of the questionnaire measures the importance of various information topics to parents. Parents are asked to rate how important each information topic is to them, now that their child has completed treatments for cancer. Topics are rated on a scale of 1 (least important) to 5 (most important).

A total of fourteen information topics are listed,

and the topics can be grouped into three categories which include the physical, psychological, and social sequelae of surviving childhood cancer. As such, a summative scale for the physical components of surviving childhood cancer is comprised of topics 1 through 6. These include: the child's diagnosis, prognosis, physical handicaps caused by the cancer and its treatments, the child's levels of energy, the chances of getting other illnesses, and the ability to have children.

A summative scale of the psychological effects of having cancer is formed by items 7 through 11. This scale includes the following topics: Feelings or emotional concerns the child might have, the child's ability to think or perform well in school, the child's relationship with siblings, the child's relationship with his/her parents, and the return to school.

A third summative scale which measures the social sequelae of surviving childhood cancer is comprised of items 12 through 14 and include these topics: the child's opportunity for marriage, the child's opportunity to buy life insurance, and the

opportunity to find employment.

b) An evaluation of the amount of information that parents receive from the staff on each information topic now that their child has completed treatments for cancer is also included.

Part II B of the questionnaire measures parents' perceptions of how much information they receive from the staff on each of the listed information topics now that their child has completed treatments for cancer. Topics are rated from A (received no information) to E (received too much information).

2. The relationship of selected demographic variables to parents stated information needs is explored. Part I of the questionnaire consists of ten questions which elicit demographic information from parents with regard to their gender, age, distance from the hospital, level of education, first language, and the child's age at the time that treatments were completed. These variables have been generated from previous studies on patient/family education.

3. A statement by parents of the kinds of emotions

they experienced in the "off-therapy" phase of their child's treatment is included. Part III of the questionnaire covers this by asking subjects to describe in their own words, their emotional experience during the "off-therapy phase" of their child's treatment. Parents are also asked to respond yes or no as to whether they would like more information about the stress that is common to families during this phase of treatment.

4. Subjects are asked to indicate whether information given to them in the "off-therapy phase" of their child's treatment is appropriately timed. Part IV of the questionnaire explores this question. Parents are asked to respond yes or no to each of five items which cover the physical, psychological and social sequelae of surviving childhood cancer.

5. Parents are asked to state their preferred educational format, as well as from which health care professional they would most prefer to receive information, for each of the five major information topics.

This is covered by Part V of the questionnaire. Parents are asked to select their preferred method

for receiving information for each of the same five topics presented in Part IV of the questionnaire. Parents are asked to select one format from a list of three which include verbal, written and audiovisual presentations. Similarly, parents are asked to indicate what kinds of information they would most prefer to receive from each of three health care professionals, ie., physician, nurse counsellor, or counsellor.

Reliability

Reliability was calculated for each subtest in Part II A and B of the questionnaire using Hoyt's Analysis of Variance Procedure. Overall reliability for Part II A was calculated as 0.87. Reliability for Part II B was determined to be 0.91. These results suggest that the internal consistency between items in the questionnaire is very good.

Validity

Content and face validity of the instrument were determined by members of the pediatric oncology team including two physicians, a nurse counsellor and two educational psychologists. Two graduate students also evaluated the questionnaire and information package for

clarity. The final version of the questionnaire was put together when unanimous agreement was reached that all items were clear and relevant to the research questions.

Data Collection

Initial contact with subjects was made by mail and all families were sent an information package. This included the following: an introductory letter, an information sheet, a consent form for each parent, a copy of the questionnaire for each parent, and two self-addressed envelopes. The information sheet instructed parents to read over all the contents of the information package before completing the questionnaire.

A written consent form was sent separately for each copy of the questionnaire. Prior to completion of the questionnaire, subjects were asked to sign this form. The form assured parents that all information which they provided would remain confidential, and that no first names or family names would appear anywhere on the questionnaire. The subjects were also informed that their child's treatment would not be influenced in any way by their participation in the study. Parents were also asked to complete the questionnaire without discussing their answers with one another.

Approximately one week after parents received the information package, the investigator contacted each family by telephone. At this time parents were asked whether they had any concerns about the study or any questions regarding the directions or questionnaire items. When questions arose, they were answered by the researcher and subjects were reminded that the researcher or members of the research team could be contacted by telephone to answer further questions.

Parents were asked to return the completed questionnaires and consent forms by mail within two weeks of having received them. When all the questionnaires were returned, the researcher made a second telephone call to a random sample of the participants. During this phone call the subjects were asked to informally comment on the questionnaire with regard to its length, the language used, and the clarity of the questions asked. Subjects were also asked to identify any important areas that they felt were overlooked in the questionnaire.

# Chapter VI

## DATA ANALYSIS

Quantitative data analysis which involved the calculation of descriptive statistics demonstrated that parents consider information about their child's prognosis, diagnosis and emotions to be the three most important information topics during the off-therapy phase of treatment. The statistical evidence also suggested that parents' perception of the amounts of information that they actually receive during the off-therapy phase, and the amount of information they would prefer to receive, differ considerably.

Information needs of the sample were also examined using one way analysis of variance (ANOVA). The independent variables included the length of time the child had been off-therapy (two groups), and parental sex. The sample was also split into Group I and Group II according to the child's disease. Group I represented parents whose children had diseases of the blood such as Acute Lymphocytic Leukemia (ALL), Acute Mylogenous Leukemia, (AML), Hodgkin's disease, and Non-hodgkin's Lymphoma. Group II was comprised of parents whose children had been diagnosed with solid tumors including:

Wilm´s tumor, Neuroblastoma, Ewing´s sarcoma, Osteogenic sarcoma, Rhabdomyosarcoma, Hepatoblastoma, and Retinoblastoma. The groupings were made because of the similarity of treatment programs. No significant differences were found in any of the above groups.

Similarly, no significant correlations were tabulated for selected demographic variables and parental information needs.

Parts IV and V of the questionnaire regarding the timing of information, and preferred educational formats were examined using frequencies and chi square analysis.

What are the information needs of parents whose children have completed treatments for cancer? This question was answered by calculating descriptive statistics for each item in Part II A of the questionnaire. Overall means for each of the fourteen items in Part II A were calculated and topics were rank ordered. The results of this analysis showed that the five most important information topics to parents at present are: 1) the child´s prognosis 2) the child´s diagnosis, 3) the child´s emotions after surviving cancer, 4) physical handicaps caused by the cancer or its treatment, and 5) the child´s relationship with the

parents. The topics that proved to be the least important are: 1) the child's opportunity for marriage, and 2) the child's opportunity for employment. Table 1 lists the information topics in their respective ranks.

---

Insert Table I about here

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Results from Part II B of the questionnaire were also valuable in assessing parental information needs. Descriptive statistics were calculated for Part II B of the questionnaire, and the results suggest that in general, parents received "some information" about each of the information topics that are listed. The mean scores from Part II B are presented in Table 2.

---

Insert Table 2 about here

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In order to further evaluate the question of parental information needs, difference scores were calculated between the responses in Part II A and Part II B of the questionnaire. The score was derived by subtracting the mean for each question in Part II B from its corresponding mean score in Part II A. A difference

Table 1

Rank Ordered Mean Scores For Part II A Measuring Degree Of Importance Of Educational Topics

| Educational Topics | Means |
|---|---|
| Prognosis | 4.76 (N=42) |
| Diagnosis | 4.64 (N=42) |
| Feelings | 4.23 (N=42) |
| Physical handicaps | 4.07 (N=41) |
| Relationship with parents | 4.05 (N=42) |
| Getting Other illnesses | 4.00 (N=42) |
| Ability to perform at school | 3.83 (N=42) |
| Relationship with siblings | 3.73 (N=40) |
| Levels of energy | 3.71 (N=42) |
| Return to school | 3.60 (N=42) |
| Ability to have children | 3.10 (N=42) |
| Opportunity for employment | 3.07 (N=42) |
| Opportunity for life insurance | 2.91 (N=42) |
| Opportunity for marriage | 2.14 (N=42) |

Table 2

Mean Scores from Part II B Measuring Amount Of Information Received By Parents

| Education Topics | Means |
|---|---|
| Prognosis | 2.57 (N=42) |
| Getting Other Illnesses | 1.88 (N=42) |
| Feelings/Emotions | 2.28 (N=41) |
| Opportunity for Employment | 1.24 (N=41) |
| Diagnosis | 2.85 (N=42) |
| Relationship with parents | 2.29 (N=41) |
| Opportunity for life insurance | 1.17 (N=42) |
| Physical handicaps | 2.36 (N=41) |
| Return to school | 1.98 (N=42) |
| Relationships with siblings | 2.14 (N=39) |
| Levels of Energy | 2.14 (N=42) |
| Ability to perform in school | 2.26 (N=41) |
| Ability to have children | 2.04 (N=42) |

score was then found for each of the fourteen items in Part II. The resulting difference scores provide a gross measure of the discrepancy between the amount of information parents now receive, and the stated importance of each topic. Results were consistent for each of the fourteen topics. The sample population indicated that less information had been received than would have been preferred. Educational topics concerning the child's prognosis, chances of getting other illnesses, and the child's feelings after having cancer had the largest difference scores. Table 3 lists the difference scores for each of the fourteen information topics in Parts II A and B of the questionnaire.

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Insert Table 3 about here

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Are there significant differences in the information needs of parents whose children have been treated for Leukemia and Non-Hodgkins Lymphoma, and parents whose children have been treated for solid tumors?

As described in the method section, three summative scale scores were formed by grouping the items in Parts II A of the questionnaire along the dimensions of

Table 3

Mean Difference Scores Rank Ordered

| | Means |
|---|---|
| Prognosis | 2.19 (N=42) |
| Getting Other Illnesses | 2.12 (N=42) |
| Feelings/Emotions | 1.95 (N=41) |
| Opportunity for Employment | 1.83 (N=41) |
| Diagnosis | 1.79 (N=42) |
| Relationship with parents | 1.76 (N=41) |
| Opportunity for life insurance | 1.74 (N=42) |
| Physical handicaps | 1.71 (N=41) |
| Return to school | 1.62 (N=42) |
| Relationships with siblings | 1.59 (N=39) |
| Levels of Energy | 1.57 (N=42) |
| Ability to perform in school | 1.57 (N=41) |
| Ability to have children | 1.06 (N=42) |

physical, psychological, and social sequelae of surviving childhood cancer. One way Anovas were calculated for each of the summative scale scores with disease type as the independent variable. No significant differences were found in the information needs of parents whose children were treated for Leukemia or Non-Hodgkins Lymphoma, and parents whose children were treated for solid tumors. ($F = .059$ $p > .05$, $F = .985$ $p > .05$, $F = 1.055$ $p > .05$).

Are there significant differences in the information needs of parents whose children recently came off-therapy (1987-88), and the information needs of parents whose children have been off-therapy for two years? One way Anovas were calculated to answer this question with length of time off-therapy as the independent variable. Results showed there to be no significant differences in the physical, psychological, and social information needs of parents whose children recently completed treatments for cancer (1987-88) and parents whose children completed treatments for cancer in 1986. ($F = 3.00$ $p > .05$, $F = .256$ $p > .05$, $F = 1.935$ $p > .05$).

Are there significant differences in the information needs of males and females in the sample? The results of

the one way Anovas showed that no significant difference exists in the information needs of males and females in the sample on each of the summative scale scores. ($F = .442$ $p.> .05$, $F = .370$ $p.> .05$, $F = .407$ $p.> .05$). Table 4 presents the results of this analysis.

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Insert Table 4 about here

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What is the relationship of selected demographic variables to parents' information needs? Multiple Regression analysis was used to determine whether the demographic variables in Part I of the questionnaire were related to stated information needs. Demographic variables included in the analysis were parental age, distance from the hospital, parental education, and the age of the child. The dependent variables used in the regression analysis were formed by calculating one difference score for each of the summative scales. A single score was calculated by grouping the difference scores according to their summative scales and computing a mean, or overall difference score for each scale. No significant correlations were found between any of the selected demographic variables ad parental information needs.

Table 4

Anova Results

Groupings

| | Summative Scales | | |
|---|---|---|---|
| | Physical | Psychological | Social |
| Disease Type | F = .059<br>p> .05 | F = .985<br>p> .05 | F = 1.055<br>p> .05 |
| Time Off-Therapy | F = 3.00<br>p> .05 | F = .256<br>p> .05 | F = 1.935<br>p> .05 |
| Male/Female | F = .442<br>p> .05 | F = .370<br>p> .05 | F = .407<br>p> .05 |

Do parents want more information about the kinds of parental stresses that are common to the off-therapy phase of treatment? The percentage of parents who responded "yes" to this question was 80.00% (N=40).

Do parents find that the information they receive now that their child has completed treatments for cancer is given to them at a "helpful time"? To answer this question frequencies were tabulated for each of the five items presented in Part IV of the questionnaire. Eighty-five % (N=34) reported that they received information on the topic of diagnosis at a "helpful time". For the item on the child's prognosis, 73.53% (N=34) said that the information on this topic was received at a "helpful time". Concerning item three, the side effects of the cancer, 73.53% (N=34) said that the information given was provided at a "helpful time". For items four and five, the emotional and social side effects of having childhood cancer, 50.00 % (N=34) of the sample indicated that the information about their child's feelings was given at a helpful time, and 47.86% (N=34) stated that information on the social consequences was received at a "helpful time".

Chi square was tabulated for each of the five items in Part IV. Chi square analysis showed that the responses to items 1, 2, and 3 in Part IV could not be attributed to random sampling, such that information about the child's diagnosis, prognosis, and handicaps caused by the cancer or its treatments, would appear to be given at a "helpful time". These results are presented in Table 5.

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Insert Table 5 about here

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What educational formats do parents prefer for different information topics? This question was answered by calculating the frequency of parents' preferences. For item one, 63.41% (N=41) indicated that they prefer to receive information about their child's diagnosis through verbal exchange. Similarly for item two, the majority of parents 63.41% (N=41) said that they prefer to receive information about their child's prognosis verbally.

The results for item three, information about the side effects of having childhood cancer, differed somewhat since 47.50% of parents said that they would prefer written information, and 32.50% (N=40) indicated

Table 5

Results Of Chi-Square Analysis On Timing Of Information

| Educational Topics | Chi-Square |
|---|---|
| Diagnosis | X obt = 15.12<br>p< .01 *<br>(N=34) |
| Prognosis | X obt = 15.31<br>p< .01 *<br>(N=34) |
| Physical Handicaps | X obt = 15.31<br>p< .01<br>(N=34) |
| Feelings | X obt = 0.0<br>p> .01<br>(N=34) |
| Social concerns | X obt = .125<br>p> .01<br>(N=34) |

that they would prefer receiving information verbally. The frequencies tabulated for item four showed that 50.00% of the sample said they would prefer to receive information about their child's feelings verbally, and 30.95% (N=41) would prefer written information on the topic of the child's feelings. As for the social consequences of having cancer 51.22% said they prefer a verbal format, and 31.71% (N=41) indicated that a written format would be preferable. These results are summarized in Table 6.

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Insert Table 6 about here

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Chi square analysis was also calculated for each of the above items. In all cases the results were significant at $p < .01$.

From whom do parents most prefer to receive information for different information topics? Concerning the topic of diagnosis, 87.80% (N=41) of parents in the sample said that they would prefer to receive this information from the physician. Regarding diagnosis, 97.56% of the parents sampled (N=41) indicated that they prefer to receive information about their child's

Table 6

Frequency Scores For Preference Of Educational Format

| Topics | Formats | | | |
|---|---|---|---|---|
| | Verbal | Written | Audio Visual | Combination |
| Diagnosis (N=41) | 63.41% | 19.51% | 4.88% | 12.20% |
| Prognosis (N=41) | 63.41% | 19.51% | 4.88% | 12.20% |
| Physical Handicaps (N=40) | 32.50% | 47.90% | 10.00% | 10.00% |
| Feelings (N=41) | 50.00% | 30.95% | 9.76% | 7.32% |
| Social Effects (N=41) | 51.22% | 31.71% | 9.76% | 7.32% |

prognosis from a physician. The majority of respondents, 73.17%, (N=41) said that they preferred to discuss information about the side effects of having cancer with a physician. The number of subjects who wished to discuss their child's feelings and the social consequences of having cancer with a physician was negligible (7.32% and 0%. N=41)

The topics that were favored to discuss with a nurse counsellor were the side effects and feelings the child might experience after completing treatments for cancer. As such, 82.93% (N=41) of the sample prefer to discuss the side effects of the disease with a nurse, and 68.29% (N=41) would choose to discuss the child's feelings with a nurse.

A significant majority of the sample also indicated that they would like to discuss their child's feelings and the social consequences of having had cancer with a counsellor. Results showed that 78.05% of the sample (N=41) prefer to receive information about their child's feelings from this health care professional. Similarly, 85.37% (N=41) indicated that they would prefer to receive information about the social consequences of surviving childhood cancer from a counsellor.

Qualitative Analysis

The aim of qualitative analysis is to draw out common experiential themes from subjects' written responses. As an investigative methodology, qualitative analysis seeks to provide an accurate description of subjects' experiences so that a clearer understanding can be obtained by the researcher (Mark & Valle, 1978). In this study, qualitative analysis was carried out by the researcher who began the analysis by carefully reading the subjects' written answers several times. On the fourth reading, prevailing themes in the data were noted and the frequency of these themes was recorded so as to provide a systematic analysis and presentation.

In Part III of the questionnaire parents were asked to describe their emotions and feelings since their child had completed treatments for cancer. The responses to the question were varied. Out of the 35 people who responded to the question, 18 of them or 51.42% said that they were relieved and happy when their child's treatments for cancer ended. Nearly as many people, (N=17) or 48.57%, said that in spite of their child's recovery, they were afraid that the disease would relapse, and 20.00% of the sample said that they

continued to feel uncertain about the future with regard to disease recurrence and possible side effects of treatment. As a result, several parents mentioned that they often overreacted to common illness symptoms such as colds, stomach aches and sore throats.

A few individuals (N=4) mentioned that in the initial stages of being off-therapy (8-12 months) they continued to experience just as much stress and worry as they did during the period of their child's treatment for cancer. Some said that they missed having contact with the staff and families at the hospital (N=4). Seven people (20%) stated that as time went by they were growing more optimistic about their child's long-term well being. A small number, N=4, stated that they had experienced a major shift in values, and had become more concerned about the quality of life since their child had cancer. Others expressed gratefulness to the pediatric oncology staff and to God (N=5). In two families, parents spoke of the loss of their marital relationship due to the stress imposed by the disease. Table 7 presents a chart of the various themes that emerged from the content analysis, and the frequency of each theme's occurrence.

Insert Table 7 about here

The content analysis of Part II of the questionnaire was more limited since only 10 out of 38 people answered this question. The question asked parents to state when it would be "helpful" to receive information about the various topics. Two predominant themes were recorded for this question. Most frequently parents (80%) said that it would be beneficial to have continuous or on-going information during the off-therapy phase of their child's treatment. The other common theme was that parents felt certain information topics would be more "helpful" if given at the time their child or family was experiencing them. Approximately three out of ten people gave this response.

Table 7

Frequency Of Themes From Qualitative Analysis

| Themes | Frequency |
|---|---|
| Relieved/Happy | 51.42% |
| Growing sense of optimism | 20.00% |
| Afraid of Relapse | 48.57% |
| Disbelief that child is cured | 11.43% |
| Uncertain of the future | 20.00% |
| Vigilant about symptoms | 14.29% |
| Overprotective of child | 5.71% |
| Grateful to God/Staff | 14.29% |
| Miss clinic visits | 14.29% |
| Improved quality of life/ Feel stronger | 11.43% |
| Change of values/priorities | 11.43% |
| Want to get back to "normal" | 11.43% |
| Sadness over loss of marriage | 5.71% |

# Chapter VII

# DISCUSSION

In review then, the questions which this study explored include the following:

1.a) What are the information needs of parents whose children have completed treatments for cancer since 1986?

b) Are there significant differences in the information needs of parents whose children recently came off-therapy (1987-88), and the information needs of parents whose children have been off-therapy for two years (1986)?

c) Are there significant differences in the information needs of parents whose children have been treated for Leukemia and Non-Hodgkins Lymphoma, and those whose children have been treated for solid tumors?

d) Are there significant differences in the information needs of male and female parents?

2.a) What is the emotional experience of parents when their child is in the off-therapy phase of treatment?

b) Do parents want more information about the kinds

of parental stresses that are common to this phase of treatment?

3. Do parents find that the information that they receive now that their child has completed treatments for cancer is given to them at a "helpful time"?

4. What is the relationship between selected demographic variables, and parents' information needs?

5.a) What educational formats do parents prefer for different information topics?

b) From whom do parents most prefer to receive different information?

Overall the results of the study are very supportive of on-going patient/family education in pediatric oncology during the off-therapy phase of treatment. The data clearly demonstrates that the majority of parents value having information about the late term effects associated with surviving childhood cancer. This conclusion in itself is important as it adds to the mounting evidence favoring the development of patient/family education (Rapoff, Purviance, & Lindsley, 1988, Rimer, Levy, Keintz, MacElwee, Engstrom, 1987;

Jacobs, Ross, Walker, & Stockdale; 1983; Swick, 1984).

Rank ordering the information topics demonstrated that information about the child's prognosis and diagnosis is "most important" to parents during the off-therapy phase of treatments. When this finding is combined with the information that parents provided about their feelings of fear of relapse, the importance of the prognosis and diagnosis is underscored; the finding is consistent with the notion of a "Damocle's Syndrome" as described by Koocher and O'Malley (1981). Lewis and LaBarbera, (1983) also reported that anxiety and fears relating to relapse were common among nineteen mothers and one father of children whose chemotherapy had been discontinued. Alby (1980), described the off-therapy phase of treatment as a difficult "weaning" or "mourning" period for both parent and patient, and suggested that it is a time of risk for the family. Authors Lewis and LaBarbera (1983) contend tnat this is a normal reaction, and it is brought about by the insidious nature of the disease. They also point out that parental and patient anxiety may arise because of the limited scientific knowledge that presently exists about cancer and its treatments.

Information about the physical handicaps caused by the cancer and its treatment and the chances of getting other illnesses were also cited as being "very important" by parents. Taken together, these results concur with other studies which suggest that information about the physical aspects of the disease are a priority for parents (Chesler and Barbarin, 1987), and continue to be a priority in the off-therapy phase of treatment (Peck, 1979).

Parents also indicated that information about their child's feelings after having cancer, and about their own relationship with the child is also "very important". This finding adds to a growing body of research literature which asserts the value of information about both the intra-personal and inter-personal late effects associated with childhood cancer. Cella (1987) in a literature review of the psychosocial effects of cancer survivors concluded that difficulties were commonly encountered among survivors in their relationships with others, as well as within themselves (eg. mood changes, self-esteem, and somatic distress).

Topics that appeared to be "moderately to very important" to parents were: the child's ability to think

and perform well in school, the child's relationship with siblings, the child's levels of energy and the child's return to the friends and routine of school. This theme has also recurred in the literature. Moore, Glasser, and Ablin, (1988) for example, found that teachers rated leukemia survivors as functioning at a level below their peers with regard to their social behavior.

Topics that ranked as being "somewhat" to "moderately important" included: the child's ability to have children, opportunities for employment, opportunities for life insurance, and opportunities for marriage. These findings seem to contrast the results of other studies such as Koocher and O'Malley (1981) and Lansky et al., (1986) in which parents said that they were very much concerned with the late term social sequelae of surviving childhood cancer. The reason for this difference is not entirely clear, however, the age group of the children in this project may be an important factor; only a small number (N=5) of adolescents were involved in this study.

No significant differences were found between the information needs of parents whose children recently completed treatments for cancer (1987-88) and parents whose children have been off-therapy since 1986.

Although no statistical differences were tabulated for the two groups, comments from parents suggest that the fear of relapse abates over time, and becomes moderated by positive experiences and recovery. As reported in the content analysis some people stated that they felt a "growing sense of optimism" about their child's health. One mother describes her experience in the following way:

> "As time passes and we move uneventfully through check-ups, I am becoming optimistic, (cautiously so).

If this trend is true for most families, then a study of parents and children who have been off-therapy for a longer period of time might contrast differences in information needs more effectively.

The fact that there were no significant differences in the information needs of male and female parents in the sample suggests that both parents are equally interested in having information about their child. This finding validates the importance of aiming clinical intervention to meet the needs of both mothers and fathers. Also relevant is the fact that a large majority of parents indicated that they would like information about family stress during the off-therapy phase of treatment. Taken together these results support numerous

researchers who favor theoretical models and interventions that are family based (McCubbin et al., 1983; Binger, 1984; Brett, 1987; Chesler & Barbarin, 1987).

No significant differences were found in the information needs of parents whose children were treated for diseases of the blood such as leukemia, and those who had been treated for solid tumors. This conclusion must be treated tentatively, needing further exploration with larger numbers of survivors and their families.

None of the demographic variables used in the multiple regression analysis were significantly correlated with parental information needs. The variables included in the analysis were: parental age, distance from the hospital, parent's education and first language. The issue of location did seem to be important to parents when informal comments about the study were gathered by the researcher in the second phone call. Several parents mentioned that living over 100 miles from the hospital was clearly a disadvantage since services were not easily accessible to them. As mentioned in an earlier chapter other investigations have demonstrated a relationship between similar variables and information

needs patients and families. (Cassileth et al., 1980; Rudolph et al., 1981, Chelser & Barbarin, 1984; Kramer & Perin, 1985) In this case the results must be interpreted cautiously due to limited sample size.

Parts IV and V of the questionnaire yielded valuable information about preferred educational formats. First, with regard to the timing of information, the majority of parents indicated that information about their child's diagnosis, prognosis and possible side effects caused by the cancer and its treatment were given at a "helpful time". Less consistent results were recorded for the topics on the child's feelings after having cancer, and the social consequences of having had cancer. Approximately half of the sample were satisfied with the timing of information in these areas, and approximately half were not satisfied. From the content analysis it was apparent that on-going information throughout the off-therapy phase of treatment would be more helpful. This need for continuity was also found in a study by Peck (1979), and is recommended by Mullan (1983). In addition, several parents indicated that they prefer to receive information when problems arise, which implies that normative developmental transitions need to be

considered when establishing educational formats for families. Several researchers and practitioners agree that developmentally relevant information is a critical consideration when providing educational intervention (Hall, 1987; Binger, 1984; Dudjak, 1987). For the most part then, information provided by the pediatric oncology staff appears to be well timed although more and continuous information is preferred by parents.

The evidence also pointed to verbal format as most preferred by parents when information about diagnosis, prognosis, feelings and social consequences is given. Most parents would like written information about the side effects of the cancer and its treatment. Research on educational formats in pediatric oncology is scarce, so this result is valuable in terms of its immediate practical application for the pediatric oncology team, however its generalizability is limited.

Finally, the data very strongly demonstrated that parents prefer to receive information about the child's diagnosis and prognosis from a physician. The nurse counsellor was the source most preferred for receiving information about the side effects of the disease.

The evidence also demonstrated that parents prefer to receive information about their child's feelings and the social consequences of the disease from a counsellor. It appears that parents prefer that each health care professional adhere to their area of competence when providing information. Similar concerns have been voiced by others (Van Eys, 1979; Lewis and LaBarbera, 1983).

The result also implies that parents would like to have their child and family dealt with wholistically. This in fact may reflect a growing public awareness that health and wellness encompass more than the physical aspects of existence (Majumdar and Carpio, 1988).

The Double A B C X model of family stress and coping presented earlier fits well with the data obtained from this study. This fit becomes more apparent when the off-therapy phase is viewed as one of a series of events that both patient and family experience in the course of being treated for cancer. This sequence of stressful events reflects what Ross (1978) has called "changing critical phases" of childhood cancer, or the typical "illness cycles" according to Adams (1979, 17-21). Most important, is that the stress of being off-therapy is related to the earlier phases of treatment. Mullan

(1983, p. 272) a physician who survived cancer speaks of it in this way:

> Permanent survival, however, has several dimensions beyond those of victory over the disease, including specifically a kinship and continuum with the previous seasons of survival.

As such, it is necessary to discuss stress and coping during off-therapy in the context of earlier phases of treatment. Most research to date suggests that the period of diagnosis and early treatments is the most stressful period for the family. Chesler and Barbarin (1987) found this to be true among the parents in their study. Other investigators note similar findings (Binger et al., 1969; Knapp and Hansen, 1973; Adams, 1979; Hamburg and Adams, 1967; McCallum and Schwarts, 1972; and Ross 1978).

If diagnosis is viewed as the precipitating crisis, or the X factor in McCubbin and Patterson's model, then events which follow it can be seen as post crisis variables. Hence, the period of treatments can be categorized as "pile-up" or the "aA" factor in the Double A B C X model. Numerous variables interact to determine how the family adapts to this difficult period, and over time, the abnormal event of having a child with cancer, becomes "normal".

When the family reaches the phase in which their child is taken off-therapy, it appears that a new stress cycles, albeit a less intense cycle, is engendered. More specifically, it is possible to conceptualize being off-therapy as a whole new "stressor" or factor "A" in the Double A B C X model. Both factor B, the family's resources, and factor "C" the family's perception of "A" (which will be influenced by the trajectory of the disease), will interact to produce X, the crisis, which presents itself in persistent fear or anxiety over the possibility of relapse.

The qualitative analysis clearly supported the influence of perceptions in mitigating the degree to which being off-therapy is a "crisis". For example, some parents believed that their child's cancer was permanently arrested and were relieved and happy. Others continued to fear the return of the cancer and expressed anxiety over minor illnesses such as colds and sore throats. Post crisis variables entail the quality and quantity of physical, psychological and social sequelae that occur during the off-therapy phase. As well, the family's resources (factor bB) and perceptions (factor cC) will interact to produce some degree of family

adaptation. According to this model, patient/family education may be viewed as one of a number of resources which can buffer the stress engendered during the phase of being off-therapy.

## Conclusions

The overall picture that emerges from the present study suggests that the majority of parents would like to receive more information about the physical, psychological and social aspects of surviving childhood cancer on an on-going basis. The kinds of concerns that were identified by parents as important are congruent with previous research in this area. The ranking of information topics does add a new dimension to the research since it highlights those areas of greatest concern in the early stages of being off-therapy, and can be useful in planning educational programs.

Also noteworthy is the fact that the majority of parents prefer to receive information through verbal exchange; they indicated in addition, that they would like to receive information from a range of health care professionals including a physician, nurse-counsellor and counsellor.

The implications of this last point are important.

Evidently, parents and families want multi-disciplinary care from health care professionals. It is especially important to recognize that counsellors have an important role to play in providing social and emotional support for patients and families who are off-therapy as well as those who become long-term survivors. This support can be accomplished by designing and implementing educational programs for parents and children, as well as by providing individual, family and group counselling.

The study also highlights the fact that there are phases to the off-therapy stage of treatment for the patient and family. Mullen (1983, p. 272) aptly calls these "seasons of survival" and describes them in the following manner:

> There is no moment of cure but rather an evolution from the phase of extended survival into a period when the activity of the disease or the likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.

It seems imperative that health care professionals become better acquainted with the phases of being off-therapy so that more sensitive and effective interventions can be implemented. Research projects such as this one, advance our knowledge in that direction.

## Limitations

This investigation was exploratory in nature and its intent was to evaluate the information needs of parents whose children have completed treatments for cancer within the last two years, and to assess parents' preference for educational formats. The obtained results make a valuable contribution to both practice and research. To some extent, however, the generalizability of the results is limited due to the size of the sample. Further investigations with larger sample sizes are very much needed.

The questionnaire itself may impose some limitations since it provides rather broad global measures. As such, it may not be sensitive to small differences in the population. Future research might aim at refining the questionnaire in order to increase its sensitivity.

Subjects were asked to comment on the questionnaire in the second telephone conversation made by the researcher. A number of subjects said that they found the question on the timing of information to be confusing. Another parent said that she would have preferred to have more open ended comments throughout the questionnaire so that she could give more context to her

responses.

Some methodological refinements could also be made. For example the order of the education topics in Part II A and B of the questionnaire could be systematically altered as a way of strengthening the research design. The rate of response to the questionnaire might be improved by developing a short form of the questionnaire which could be given over the telephone to parents who do not return their mailed copy. Issues such as these need to be addressed should the questionnaire be implemented with a wider sample.

## Future Research

On-going research might seek to elaborate on some of the concerns that were touched upon in this study. The needs of children and adolescents who have survived cancer need to be more thoroughly explored in research. It might be valuable to develop an instrument which evaluates the information needs of this population. Developing an educational program and testing its effectiveness on patients and families who are in the off-therapy phase of treatments is another direction that could be addressed by future research.

Finally, this study could be replicated with a larger

sample size which includes patients and families who have been in the off-therapy phase for a longer period of time. Also, the same questionnaire might be used with larger groups of two or three particular disease types in order to highlight the special concerns of these groups. Clearly, there remain many viable and important areas to explore in continued research on patient/family education in pediatric oncology.

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# Appendix A

## Specimen Information Package for Parents

INTRODUCTORY LETTER

Dear Mr. & Mrs. _____:

My name is Lori Dyni. I am a student completing a Masters of Education degree in Counselling Psychology within the Department of Educational Psychology, (Supervisor, G. Kysela, Ph. D. ). I am writing to you on behalf of the pediatric oncology team at the Cross Cancer Institute.

For the past several months, , Dr. Yanofsky (principle investigator), Judy McTavish (co-investigator) and I (co-investigator), have been developing a research project which investigates the information needs of parents whose children have successfully completed treatments for cancer. In order to gain a better understanding of these needs, a questionnaire has been developed which you, along with all other families whose children have successfully completed treatments for cancer since 1986, are being invited to complete. Attached to this letter is a more detailed description of the purpose of the study and the activities involved in completing the questionnaire.

We recognize that this topic can be a sensitive one, and we want to reassure you that your identity will remain confidential if the results of the study are published. We also want to make it clear to you that your child's care will not be affected by whether or not you decide to participate in the study.

In one week's time I will contact you by telephone to describe the study once again to you, and answer any questions or concerns that you may have.

Your contribution to our study may help us to grow in our understanding of your needs, as well as to provide more effective health care to all families that we serve. I trust that you will give this your full consideration, and thank-you for your time.

Yours truly,

# INFORMATION SHEET

An Evaluation of Patient/Family Education in

Pediatric Oncology:
The Off-Therapy Phase

Principle Investigator: R. Yanofsky, M.D.
Co-Investigators: Judy McTavish, R.N., BSc.N.
and Lori Dyni, B.A. Psychology, M.Ed. in
Counselling Psychology (in progress)
(Supervisor, G. Kysela, Ph.D.)

In collaboration with the Department of Pediatrics, Cross Cancer Institute.

Dear Parents:

This information sheet is comprised of two parts. Part I describes briefly the nature and purpose of the study.

## Part I

## DESCRIPTION OF THE STUDY

The major purpose of this study is to find out what kinds of information are most important to parents after their child has successfully completed treatments for cancer.

Past research has shown that patients and families often deal more effectively with the stresses caused by having a family member who is ill, when they are given appropriate information about various aspects of the disease and the side effects caused by the disease and its treatment. Children who are long term survivors of cancer have special needs which researchers have only begun to understand. There is some evidence to suggest that the "off-therapy phase" of treatment of childhood cancer can be a time of unique stresses and difficulties for both patient and family. To date, the information we do have about the nature of those stresses and concerns, is incomplete. As such, this project can contribute to our understanding of the concerns of long term survivors and their families, and in time, will improve our service to the community.

## Part II

Part II of the information sheet describes the steps that each parent must take in order to participate in the study. It is essential that each parent carefully read through Part II of the information sheet and follow the directions given.

### DIRECTIONS FOR PARTICIPATING IN THE STUDY

1. Read all information provided in the information package. The package includes one letter of introduction, one information sheet, as well as one consent form and one questionnaire for each parent.

2. Make a note of any questions or concerns that you have about the questionnaire or the study.

3. Discuss questions with Lori Dyni, when she contacts each family by telephone. Telephone calls will be made approximately one week after each family receives the information package.

4. Read and sign the informed consent; have someone witness your signature.

5. Return the informed consent form(s) by mail in the envelope marked "Informed Consent Forms".

6. Complete the questionnaire.
The questionnaire should be completed individually, which means that spouses should not discuss their answers with one another until after each has completed the questionnaire.

7. Return the questionnaires by mail in the envelope marked "Questionnaires".

8. Discuss your impressions of the questionnaire with Lori Dyni, when she contacts each family by telephone for a second time. Telephone calls will be made after the questionnaires have been returned to the researcher.

9. Altogether it should require 30-40 minutes to complete the questionnaire. Parents are reminded that their family name will not appear on any part of the questionnaire.

10. Parents can indicate that they would like a summarized copy of the results by placing a check mark by this question at the end of the consent form.

# INFORMED CONSENT FORM

Project Title: An Evaluation of Patient/Family Education in Pediatric Oncology: The Off-Therapy Phase

Principle Investigator: R. Yanofsky, M.D.
Co-investigators: Judy McTavish, R.N., B.Sc.N.
and Lori Dyni, B.A. Psychology, M.Ed. in Counselling Psychology (in progress)
(Supervisor, G. Kysela, Ph.D.)

In collaboration with the Department of Pediatrics, Cross Cancer Institute

I_____ consent to participate in the study entitled, "An Evaluation of Patient/Family Education in Pediatric Oncology: The Off-Therapy Phase." I acknowledge that the research procedures described on the Information Sheet, and of which I have a copy, have been explained to me, and that any questions that I have asked have been answered to my satisfaction. I know that I may contact the investigators if I have any further questions. I understand that I am free to withdraw from the study at any time without jeopardy to my child's continuing medical care. I have been assured that all personal information relating to this study will be kept confidential.

I give my permisssion to include relevant details from the questionnaire or our conversations in the final report, on the understanding that any specific details which can be identified with my family will be removed.

I am aware that a summary of results of this study will be sent to me if I so request.

I also understand that:

I I will be asked to fill out a questionnaire which requires 30 to 40 minutes of time. If there are questions in the questionnaire that I prefer not to answer, I am free to choose that option.

2. My participation in this study is voluntary and I can terminate my participation in this study at any time.

3. My name and family name will not appear on the questionnaire.

Initials _____

Project Title: An Evaluation of Patient/Family Education in Pediatric Oncology: The Off-Therapy Phase

4. The content of my answers in the questionnaire will be held in confidence, although I am free to discuss this content with whomever I desire.

5. I will receive two telephone calls from the investigator. The content of these conversations will be held in confidence.

6. I may not necessarily directly benefit from participating in this study.

7. My child's care will not be influenced in any way by my participation or non-participation in the research project.

8. Should the content of the questionnaire evoke any painful memories and/or emotions, I am aware that the support of the researcher and/or the Nurse Counsellor of the pediatric oncology team of the Cross Cancer Institute and/or Support services of the Cross Cancer Institute are also available to me or any member of my family.

The persons who may be be contacted about the research:

Lori Dyni

1-(403) 433-0771
Telephone No.

Judy McTavish

1-(403) 432-8512
Telephone No.

R. Yanofsky, M.D.

1-(403) 432-8512
Telephone No.

_____
(Signature)

_____
(Witness)

_____
(Date)

Would you like a summarized copy of the results of the study?

_____ yes _____ no

No. _____

# QUESTIONNAIRE

An evaluation of patient/family education in pediatric oncology:
The off-therapy phase

WE VALUE YOUR PARTICIPATION IN THIS STUDY. WE ARE CONDUCTING THIS RESEARCH PROJECT BECAUSE WE WANT TO BETTER UNDERSTAND THE CONCERNS THAT YOU , AS PARENTS HAVE, AND TO DETERMINE THE KINDS OF INFORMATION YOU WANT AND NEED AFTER YOUR CHILD HAS COMPLETED TREATMENTS FOR CANCER. INFORMATION OBTAINED FROM THIS STUDY MAY ENABLE US TO TO PROVIDE BETTER SERVICE FOR ALL PARENTS AND CHILDREN WHO COME TO OUR CLINIC.

Principle investigator: R. Yanofsky, M.D.
Co:investigators: Judy McTavish, R.N., B.Sc.N
Lori Dyni ( Supervisor, G. Kysela, P.h.D)
In collaboration with the Department of Pediatrics, Cross Cancer Institute

This questionnaire is divided into five parts.

Part I asks that each parent fill out some personal information. The purpose of these questions is to find out if people from similar backgrounds share common concerns once their child has finished treatments for cancer.

Part I.

Please put a check mark ___ on the line beside the correct answer, unless different instructions are given.

1. I am

_____female _____male

2. My age is

_____ 20-29
_____ 30-39
_____ 40-49
_____ 50 and over

3. I live

_____ within the city of Edmonton
_____ within 50 miles of the city of Edmonton
_____ 50-100 miles outside the city of Edmonton
_____ more than 100 miles outside of Edmonton

4. I have

_____ completed some high school
_____ high school diploma
_____ technical or other post-secondary schooling

5. My ethnic background is

_____

_____

6. English is my first language?
_____ yes

If no, please state your first language. _____

7. I am the child's

_____ mother
_____ father
_____ step-mother
_____ step-father

8. My child's diagnosis was/is:
(check one of the following)

Group II

- ☐ Acute lymphoblastic leukemia (A.L.L.)
- ☐ Acute myelogenous leukemia (A.M.L.)
- ☐ Hodgkin's disease
- ☐ Nonhodgkin's lymphoma or Burkitt's lymphoma

Group III

- ☐ Wilms' tumor
- ☐ Neuroblastoma
- ☐ Ewing's sarcoma
- ☐ Osteogenic sarcoma
- ☐ Rhabdomyosarcoma or other muscle cancers
- ☐ Liver cancer (Hepatoblastoma or hepatocellular carcinoma)
- ☐ Retinoblastoma
- ☐ Other . Specify: _____

9. My child, at the time she/he completed treatments was

_____ infancy to 5 years
_____ 6 to 12 years
_____ 12 to 18 years

10. My child is

_____ female _____ male

Part II

Part II of the questionnaire is made up Sections A and B.

Section A

The purpose of section A is to find out HOW IMPORTANT each of the following kinds of information are to YOU NOW that your child has completed treatments for cancer.

Please rate each topic from 1 (least important) to 5 (most important) by circling the correct answer.

| least important 1 | somewhat important 2 | moderately important 3 | very important 4 | most important 5 |
|---|---|---|---|---|

Now that your child has completed treatments for cancer,
HOW IMPORTANT IS IT TO HAVE INFORMATION ABOUT YOUR CHILD'S .....

| | | | | | |
|---|---|---|---|---|---|
| 1. Diagnosis - the state of the disease at present | 1 | 2 | 3 | 4 | 5 |
| 2. Prognosis - the future condition of your child's health | 1 | 2 | 3 | 4 | 5 |
| 3. Physical handicaps caused by the cancer and its treatments | 1 | 2 | 3 | 4 | 5 |
| 4. Levels of energy | 1 | 2 | 3 | 4 | 5 |
| 5. Chances of getting other illnesses | 1 | 2 | 3 | 4 | 5 |
| 6. Ability to have children | 1 | 2 | 3 | 4 | 5 |
| 7. Feelings/Emotional concerns | 1 | 2 | 3 | 4 | 5 |
| 8. Ability to think and perform well in school | 1 | 2 | 3 | 4 | 5 |
| 9. Relationships with his/her brothers and sisters | 1 | 2 | 3 | 4 | 5 |
| 10. Relationship with you | 1 | 2 | 3 | 4 | 5 |
| 11. Return to the friends and routine of school | 1 | 2 | 3 | 4 | 5 |
| 12. Opportunity for marriage | 1 | 2 | 3 | 4 | 5 |
| 13. Opportunity to buy life insurance | 1 | 2 | 3 | 4 | 5 |
| 14. Opportunity to find employment | 1 | 2 | 3 | 4 | 5 |

Section B

Please tell us how much information you feel that you receive from the staff on each of these topics, NOW that your child has completed treatments for cancer.

To complete section B, please rate each topic from 1 (receive no information) to 5 (receive too much information), by circling the correct response.

| no information | some information | just enough information | much information | too much information |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Now that your child has completed treatments for cancer
HOW MUCH INFORMATION DO YOU RECEIVE ABOUT YOUR CHILD'S .....

| | | | | | |
|---|---|---|---|---|---|
| 1. Diagnosis - the state of the disease at present | 1 | 2 | 3 | 4 | 5 |
| 2. Prognosis - the future condition of your child's health | 1 | 2 | 3 | 4 | 5 |
| 3. Physical handicaps caused by the cancer and its treatments | 1 | 2 | 3 | 4 | 5 |
| 4. Levels of energy | 1 | 2 | 3 | 4 | 5 |
| 5. Chances of getting other illnesses | 1 | 2 | 3 | 4 | 5 |
| 6. Ability to have children | 1 | 2 | 3 | 4 | 5 |
| 7. Feelings/Emotional concerns | 1 | 2 | 3 | 4 | 5 |
| 8. Ability to think and perform well in school | 1 | 2 | 3 | 4 | 5 |
| 9. Relationships with his/her brothers and sisters | 1 | 2 | 3 | 4 | 5 |
| 10. Relationship with you | 1 | 2 | 3 | 4 | 5 |
| 11. Return to the friends and routine of school | 1 | 2 | 3 | 4 | 5 |
| 12. Opportunity for marriage | 1 | 2 | 3 | 4 | 5 |
| 13. Opportunity to buy life insurance | 1 | 2 | 3 | 4 | 5 |
| 14. Opportunity to find employment | 1 | 2 | 3 | 4 | 5 |

Part III.

In your own words, how would you describe your own feelings/emotions since your child has successfully completed treatments for cancer?

_____

_____

_____

_____

_____

(use back of page if necessary)

Would you have found it beneficial to have information about parent/family stress in the "off-therapy phase" of your child's treatment?

_____ YES _____NO

Part IV.

Please tell us whether the information that you now receive for each of the following topics is given to you at a "helpful time".

| | | |
|---|---|---|
| 1. Diagnosis | YES | NO |
| 2. Prognosis | YES | NO |
| 3. Physical side-effects from the cancer or treatments | YES | NO |
| 4. Feelings /emotional concerns that your child might have | YES | NO |
| 5. Possible social consequences that your child may face | YES | NO |

If the time that you receive certain information is not helpful, please tell us when would be a helpful time.

_____

_____

_____

_____

_____

_____

(use back of page if necessary)

Part V.

Please tell us which one of the educational formats you would most prefer for receiving information about each of the following topics. Please circle one answer for each question.

EXAMPLES: A verbal format could be an individual discussion with one health care professional in which information was given and individual questions could be answered.
A written format could involve receiving a pamphlet or information package which explained various aspects of a particular topic.
An audiovisual format could involve the presentation of a film or video and would probably be presented to a small group of parents and/or families at once.

| | | | |
|---|---|---|---|
| 1. Diagnosis | Verbal | Written | Audiovisual |
| 2. Prognosis | Verbal | Written | Audiovisual |
| 3. Possible physical side effects caused by cancer or treatment | Verbal | Written | Audiovisual |
| 4. Feelings/emotions that your child might have | Verbal | Written | Audiovisual |
| 5. Possible social consequences that your child might face | Verbal | Written | Audiovisual |

Please circle what kinds of information would you most prefer to receive from each of the following health care professionals. You may circle more than one topic for each health care professional listed.

Note: counsellor refers to an individual trained to help people with the social and emotional concerns of having cancer

| | | | | | |
|---|---|---|---|---|---|
| Physician | Diagnosis | Prognosis | Possible side effects caused by cancer or treatments | Feelings/emotions your child might have | Social consequences your child might face |
| Nurse-Specialist- Pediatric oncology | Diagnosis | Prognosis | Possible side effects caused by cancer or treatments | Feelings/emotions your child might have | Social consequences your child might face |
| Counsellor (with special training in oncology) | Diagnosis | Prognosis | Possible side effects caused by cancer or treatments | Feelings/emotions your child might have | Social consequences your child might face |

If you have any questions or concerns please contact:

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# Appendix B

## Cancer in Children

## CANCER IN CHILDREN

At this point this paper will briefly describe the disease of cancer, and its treatment. The purpose of this section is to provide a more comprehensive context in which to interpret the results of the present study, particularly for those without a medical background. Accordingly, a brief description of each of the disease types that are represented in the sample are presented.

Treatment protocols described here reflect the kind of procedures children in this study received at the time of their treatment. Present treatment regimes for cancer do differ from those described here because of rapid advances in treatment technologies.

The information has been condensed and simplified since fuller explanations are beyond the scope of this paper.

### The Disease

Cancer is actually a term used to describe a group of diseases. Each disease type has its own name, its own treatment protocol, and its own chances of cure or control. The characteristic that is common to all forms of cancer is the uncontrollable growth of a particular cell or group of cells. As such cancer may take the form

of leukemia, which develops from white blood cells, or solid tumors, which may be found in any part of the body.

Leukemia

Leukemia is the most common neoplasm in North American white children. Hockenberry and Coody (1986) report that leukemias account for approximately 30% of all childhood neoplasms in the U.S. occurring slightly less frequently among black children.

Leukemia is a cancer of the blood which develops in the bone marrow, where blood cells are produced. Three kinds of cells are produced in the bone marrow and these include red blood cells, platelets and white blood cells. White blood cells grow from immature white blood cells called blasts or lymphoblasts. Blasts that remain immature and do not function like normal white blood cells are called leukemic blasts. Leukemic blasts accumulate in the bone marrow and they begin to crowd out the normal cells that develop there. The child's symptoms will depend on the kind of blood cells that are being inadequately manufactured in the bone marrow. For example, if blood cells are being crowded out by leukemic cells, the child's blood will look thin and the patient will look pale. Other symptoms include fatigue; an

indication of low numbers of platelets produced in the bone marrow might be unusual bruising or bleeding problems.

Leukemia itself consists of more than one disease and there is actually more than one kind of leukemia for each of the major types of white blood cells (neutrophils, lymphocytes and monocytes).

Treatment

Treatment for leukemia generally consists of a combination of chemotherapy, where several anticancer medications are administered to control or eradicate the disease. Chemotherapy might also be accompanied by radiation, blood transfusions, antibiotic therapy. Bone marrow transplantations are attempted with some forms of leukemia.

The goal of treatment is to bring about a complete remission, which is a disappearance of the cancer. The two main phases of treatment are called remission induction and remission maintenance. If detectable cancer is eliminated in remission induction, then the aim of maintenance therapy is to eradicate undetectable cancer cells. Maintenance therapy may go on for months or several years.

Solid Tumors

Tumors are collections of abnormally growing cells; not all tumors are cancerous. Solid tumors are further distinguished by their cell composition. More specifically, cancers of connective or supportive tissue such as bone or muscle are called sarcomas. Carcinomas are cancers which originate from the body's glandular and epithelial cells which line body tissues. Cancers of the lymphoid organs (lymph nodes, spleen, and thymus) are lymphomas.

Lymphomas

Lymphomas have been broadly divided into Hodgkin's disease and Non-Hodgkin's lymphoma. Symptoms associated with Hodgkin's disease may be a painless swelling in the neck, armpit or groin. Hodgkin's disease rarely occurs in younger children.

Non-Hodgkins lymphoma in children is more likely to arise in the bowel or the upper mid-section of the chest. Clues that might signal the presence of Non-Hodgkin's lymphoma are abdominal swelling, breathing difficulties, swallowing difficulties or swelling of the face and neck.

Diagnosis of lymphomas can only be definitively made

through a biopsy. In order to evaluate the extent of the disease, further tests, such as CAT scans, x-rays, isotope scans, blood tests and ultrasound may be carried out.

In both Hodgkin's and Non-Hodgkin's Lymphomas, chemotherapy is the preferred treatment, and occasionally radiation therapy or surgery are combined with chemotherapy.

Brain Tumors

Brain tumors are the second most common cancers of childhood, and they are seen most frequently in children between the ages of 5-10 years old.

Numerous symptoms such as headaches, vomiting, irritability, changes in sleeping or eating habits, lethargy or clumsiness may indicate a possible brain tumor. Since these symptoms may accompany other diseases, diagnostic tests such as skull x-rays, obtain scan, and CAT scans are used to confirm diagnosis.

Treatment will depend on the type of tumor involved, and generally speaking, surgery and radiation therapy are used. Recently, chemotherapeutic agents have been administered to brain tumor patients as well.

Neuroblastoma

Neuroblastoma is a cancer which occurs only in children, and it arises from young nerve cells that develop abnormally. The majority of these tumors occur in the adrenal glands, which are located near the kidneys. As such, symptoms which may mark the presence of neuroblastoma are listlessness, persistent diarrhea, a mass, and pain in the abdomen or elsewhere.

A variety of tests are necessary for diagnosis, and these tests include intravenous pyelogram, blood tests, ultrasound echo studies, biopsy and other procedures depending on the site of the cancer.

Surgery is normally the first treatment route used, although chemotherapy and radiation therapy might also be used to prevent metastases.

Wilms' Tumor

Wilms' tumor is a cancer that originates with cells in the kidney. It is rarely seen in adults and typically occurs in children from infancy to 15 years of age. Early symptoms that are associated with Wilms' tumor include a swelling or lump in the child's abdomen, blood in the urine, weakness, fever, loss of appetite or abdominal pain. The diagnostic test battery includes a

number of radiographic tests such as abdominal chest films, abdominal ultrasound, intravenous pyelogram, organ and bone scans, as well as other hematologic and biochemical studies.

Treatment for Wilms' tumor consists of a combination of surgery, radiation therapy, and chemotherapy. The way in which these methods are used depends primarily upon the stage of the disease.

Retinoblastoma

Retinoblastoma is a rare cancer of the eye. Evidence of the disease can be seen by looking at the young person's eye, but is is normally diagnosed by examining the interior of the eye using an ophthalmoscope. Since the disease can spread to other parts of the body, it is necessary to conduct other tests such as x-rays, bone marrow aspirates, lumbar punctures and bone scans to determine the extent of the cancer.

Treatment of Retinoblastoma varies according to the stage of the disease; with early diagnosis, the tumor can be treated with radiation, and normal vision preserved. If the disease is more advanced it may be necessary to remove one eye. If both eyes are affected, every effort is made to preserve vision in at least one eye.

Rhabdomyosarcoma

Rhabdomyosarcoma arises from the muscle cells. The incidence of this form of cancer is slightly greater in males, usually affecting children between the ages of 2 and 6 years of age.

The symptoms of rhabdomyosarcoma are usually quite obvious since a noticeable lump or swelling is typically present. A biopsy is necessary to make a conclusive diagnosis, although x-ray, tomogram, gallium scan, bone scan and bone marrow examination are required to determine the spread of the disease.

Traditional treatment modes have been surgery followed by chemotherapy and radiation. In some cases, however a large tumor may need to be reduced with radiation or chemotherapy before surgery can occur.

Osteogenic Sarcoma

Osteogenic sarcoma is the most common type of bone cancer among children, and it arises in the ends of the bones. Normally this form of cancer occurs in young people between the ages of 10 and 25 years, and is more common among males than females.

Symptoms which may indicate osteogenic sarcoma are pain and swelling, although the disease can be easily

confused with numerous other problems. Biopsy is required to confirm diagnosis, and the extent of the disease is tested by x-rays, lung tomograms, CAT scans and bone scans.

Treatment usually involves amputation of the affected limb, followed by a course of chemotherapy using several anti-cancer drugs.

Ewing's Sarcoma

Ewing's sarcoma is another form of bone cancer, but it affects a different part of the bone, the bone shaft. Unlike Osteogenic Sarcoma, which is usually found in the long bones of the arm and leg, Ewing's Sarcoma tends to occur in other bones such as the ribs. Typically, the disease is diagnosed in young people between the ages of 10 and 25 years. It is seen more frequently in males, and often spreads to other bones and the lungs.